Lay participation in care in a hospital setting : an action research study.

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LAY PARTICIPATION IN CARE IN A HOSPITAL SETTING: AN ACTION RESEARCH STUDY

by

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The thesis is dedicated to the work and friendship

of

Belinda, Cathy and Mary

"We are entering in an exciting era of transition from a professionally dominated world of service to one of self-service. The process of demystifying medicine and demedicalizing society is just now rising in our consciousness as a profound turning point in the history of health. We must come to terms with changing patterns of morbidity, emerging pluralism in chronic disease care, less rigid and moralistic perspectives on avoidance of risk, recognition of iatrogenic effects, and appreciation of the lay resource as the primary and least dangerous health resource."

Levin (1978) p175

ABSTRACT

This case study sets out to explore the issues and problems of introducing lay participation in care within the context of a hospital environment. Using an action research approach, the researcher worked together with a multidisciplinary team, on a general medical ward, to facilitate a change in practice that would allow patients and their family and friends to be more involved in care.

A multi-method approach to data collection was taken including structured instruments, semi-structured interviews and participant observation. Qualitative data were systematically analysed for underlying themes and quantitative data were examined for changes over time using standard non-parametric tests.

Findings suggest that health professionals in the study had a limited understanding of lay participation in care and were professionally ignorant with respect to the concept's philosophical and political underpinnings. Some health professionals expressed serious reservations about lay participation in care and, fearing a conspiracy, were reluctant to apply the concept in their health care practice. Whilst some positive changes could be claimed, numerous difficulties were encountered in trying to change health care practice. Main barriers to change included participants' general reluctance to change practice, a lack of enthusiastic leadership to guide the change and poor multidisciplinary teamwork. The potential need for cultural change in hospital ward organisation is addressed.

Whilst it is acknowledged that case study findings cannot be generalised, some important issues can be raised. The study highlights the need for health professionals to learn to work together as equal partners and hold common philosophical understandings and approaches to care in order that innovations in practice do not flounder. Given the social trends towards individualism and the constant flux of change within the health service, the study's findings are of direct relevance to all those working in health care practice and policy.

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ABBREVIATIONS

ACHCEW	Association of Community Health Councils for England and Wales
ADL	Activities of Daily Living
ADNS	Assistant Director of Nursing Services
B/P	Blood Pressure
C/N	Charge Nurse
CARN	Collaborative Action Research Network
CHD	Coronary Heart Disease
CNM	Community Nurse Manager
Cond	Condition
DN	District Nurse
DNS	Director of Nursing Service
DNS	Director of Nursing Service
DoH	Department of Health
F/B	Fluid Balance
IV	Intravenous
J	Medics, Nurses and Paramedics combined
LPC	Lay Participation in Care
M	Medics
MDT	Multidisciplinary team
N	Nurses
NG	Nasogastric
NHS	National Health Service
P	Paramedics
Prevt	Prevention
RCN	Royal College of Nursing
RGN	Registered General Nurse
S/N	Staff Nurse
Sen. Reg	Senior Registrar
SNM	Senior Nurse Manager
SPSS-X	Statistical Package for the Social Sciences
Trtmt	Treatment
TTAs	Drugs to take away
UKCC	United Kingdom Central Council for Nursing, Midwifery and Health Visiting

CHAPTER 1

THE STORY

INTRODUCTION

This thesis is based on a study that took an action research approach to examine the issues and problems of introducing lay participation in care within a hospital setting. Action research is part of a new paradigm of research (Reason and Rowan, 1981), which holds a different philosophical perspective from more traditional research studies. The nature of this type of research and its legitimacy as a science are explored in more detail in Chapter 2 and it is important for the reader to engage with this philosophical debate in order to judge the relevance of this thesis to the contribution of social knowledge. New paradigm research is concerned with doing research with and for people, rather than on people. It supports the notion that the advancement of science and the improvement of human welfare are best achieved by devising strategies in which research and actions are closely linked. Such studies, therefore, involve practitioners in the field of identifying their practical concerns and exploring ways of overcoming issues within the murky waters of reality. It seeks to involve practitioners in the creative thinking that goes into a research enterprise by giving opportunity for participants to act as co-researchers by contributing both to the action that is the subject of the research and to the methods of the inquiry. Unlike more orthodox forms of research that may or may not lead to change in practice and social improvement, such a collaborative inquiry is seen to be a form of education, personal development and social action (Reason, 1988). Its contribution to the body of social knowledge is through the production of a different type of knowledge thought to be eminently more useful to practice. Schon (1983) describes a crisis in professional knowledge and a need to move away from "technical rationality" to "reflection-in-action". The study adds to the body of social knowledge by reflecting on health professionals' perceptions of lay participation in care when confronted with its application to their everyday practice. It further adds to the body of practical knowledge by examining the issues and problems of trying to change practice within the constraints of the health service.

New paradigm research goes beyond positivist and interpretive views of science. It challenges the positivist assumption of an objective reality and whilst it acknowledges the interpretive view of reality as being subjectively structured, it claims that both the positivist and interpretive approaches are severely limited in that they pursue the same methodological aim of describing social reality in a neutral, disinterested way (Carr and

Kemmis, 1986). In this action research study, which involved me working as a facilitator-researcher with a multidisciplinary team for a period of one year, I make no claim to being neutral and disinterested . However, whilst acknowledging my own subjectivity, I endeavour to write this account free from bias by representing the various participant perspectives.

This type of research acknowledges the role of "self" in social inquiry (Berg and Smith, 1988) and requires the study to be written as a self-reflective account. For this reason, the thesis is written in the first person and addresses not only the issues relating to the topic under study, namely lay participation in care, but also issues relating to the process of changing practice which takes into account the relationship between the researcher and the researched. A special section of the thesis (Chapter 10) is devoted to examining the issues which emerged for both the participants and the researcher in using this clinical method of inquiry.

The thesis is written as a case study in sufficient contextual depth to invite the readers to judge its relevance for themselves in their own practical situation. It is, therefore, appropriate to begin by telling the story of events to set the research in context. A summary of events in relation to time is given in Appendix I; but in telling the story I have not particularly dwelt on time as often initiatives were on-going and it is hard to delineate when they began, flourished, floundered or were disbanded. Such is the nature of researching in practice. In order to protect the identity of the participants, all medics are described as male and all the paramedics and nurses as female. In reality, whilst all paramedics were indeed female, there were both female medics and male nurses who took part in the study. Given that reflection on practice is inevitably political (Kemmis, 1985) and that individuals within case studies are easily identifiable, it is crucial to protect the identity of the participants. Medics have been labelled as male, first, because the majority were indeed of that gender, and second, issues related to gender were found to be important in the study.

BACKGROUND TO THE STUDY

Origins of proposal

The study arose from previous work (Brooking, 1986) that looked at developing a scale with which to measure attitudes towards patient and family participation in care. Brooking (1986) identified the limitations of trying to measure complex, abstract concepts and called for a smaller qualitative intervention. In 1987, the present study attracted funding by way of a Junior Research Studentship from King's College London.

Rationale for study

The rationale for the study can be located in both the literature and in my own personal interest in the topic.

Influences from the literature

Lay participation in care can be seen as a broad umbrella heading for many different aspects of and approaches to health care practice. Chapter 3 explores in more detail what is meant by the concept but to some extent the study draws on McEwen's definition:

> *"- the process whereby a person can function on his or her own behalf in the maintenance and promotion of health, the prevention of disease, the detection, treatment and care of illness and adaptation to continuing disability. It may occur independently of, or within, the existing system of care and extends to activities performed on behalf of others (e.g. family participation) and in the planning, management and evaluation of health care provision.*
> (McEwen, 1985, p.320)

Lay participation in care is seen as a major thread in health promotion (Kickbusch, 1981) and clearly McEwen's (1985) somewhat global definition embraces this important issue. However, one of the limitations of McEwen's definition lies in its failure to address some of the philosophical underpinnings of lay participation in care. In many ways lay participation in care shares some of the philosophical understandings of contemporary action research in that it is more about a philosophical approach to care than the mechanistic function of routine health care practice. In much the same way as action research is part of a new paradigm concerned with doing research *with* and *for* people rather than *on* people (Reason, 1988), so too is lay participation in care in that it is concerned with emancipating health care practice. Unlike the traditional approaches to care based on rational technology and reliance on medical expertise, lay participation in care encourages lay people to be self reflective and questioning about their needs and health care provision. In other words it is prepared to embrace alternative approaches to health care . Furthermore as with action research, lay participation in care is not regarded as a neutral, value-free process but more as a supporting and questioning initiative. This constitutes a radical change to health care practice and requires health professionals to move away from their traditional roles of *doing* things for patients and to develop more *educative, supportive and facilitative* roles. Lay participation in care, like action research, emphasises a humanistic view of nature showing more awareness of and respect

for the integrity of the individual. It also advocates a patient-centred, holistic approach to care which does not focus on patients as disease entities but instead emphasises the individual's unique perceptions of health and well-being. Clearly such an approach relies more heavily on the personal and interpersonal skills of the health care professional, in that it is dependent on the meanings and interpretations of patients or clients' desires for health care. Furthermore as with action research, lay participation in care bases its practices on democratic participation and is concerned with enabling patients or clients to identify and expose those aspects of care which are not to their liking. Similarly it seeks through empowerment to enable lay people to overcome their problems and eliminate their frustrations, working not only at the individual level but also at the social change level. Thus lay participation in care can be regarded as political and sharing many of the underlying concepts in Habermas' (1972) critical social science. These concepts and values include: holism, partnership, public participation, collaboration, equity, co-operation and enabling; all of which are identified as central to current thinking in health promotion (Dines and Cribb, 1993).

The present study, examines lay participation in care in practice rather than as a hypothetical concept described in previous research (Pankratz and Pankratz, 1974; Citron, 1978; Lin and Lewis, 1979; Brooking, 1986). Given that lay participation in care constitutes a radical change to health care practice, I believe it is important to examine closely the professional response to such an initiative. From my review of the literature, lay participation in care is generally viewed positively by both health professionals and lay people (Brooking, 1986). However, other research suggests that health professionals pay mere *tokenism* to the concept (Brownlea, 1987) and rather than offering empowerment, use lay participation in care as a form of *manipulation towards compliance* (Brearley, 1990). Furthermore it is suggested that patients themselves appear to be *reluctant collaborators* in health care practice (Waterworth and Luker, 1990). Such inconsistencies in perception cause me to question whether what people (professional and lay) think they do in theory may indeed be at variance with what they choose to do when confronted with the concept in reality. I question whether health professionals are adequately prepared to offer lay participation in care and whether society in general is ready for these changes. Whilst I believe that it is a human right for people to choose to be involved in their own care, I am also aware that demographic trends have resulted in policies being formed which emphasise individual responsibility for health (Parker, 1985) and feel concerned that a concept so rooted in humanistic principles may be further promulgated due to economic need. This concern continues as more recent reports place emphasis on partnership in care within a climate of economic stringency (Department of Health, 1989a; Department of Health, 1989b; Department of Health, 1992; Department of

Health, 1993a; Department of Health, 1993b). I also question whether, given that research has shown that the vast majority of care in the community is given by informal carers (Parker, 1985), sufficient opportunity is being taken in hospital for preparing patients and their family and friends for earlier discharge from hospital. Perhaps lay participation in care in hospital should better prepare lay people for the caring roles they are increasingly being expected to play in the community.

Such issues arising from the literature highlight the need to examine lay participation in care in a realistic setting, in particular by focusing on the various professional, lay and political understandings of lay participation in care as well as the issues and problems surrounding its implementation in a hospital setting. Given the similar philosophical foundations to lay participation in care, action research would seem an ideal method for exploring further this concept. This method of research requires reflexivity and acknowledges subjectivity, and the following section explores my personal reasons for being interested in conducting the study.

Personal interests

My interest in lay participation in care stems largely from influences in family background, education and career which impressed upon me the importance of humanism, equality and change.

I had a sheltered up bringing within a loving middle class family. Although I am now not deeply religious, my education at a local Church of England school profoundly influenced my decision to enter nursing. Humanism with its concern for the whole person, in the context of his or her family and society is part of the Church of England's teaching. It is seen to be currently in vogue as a philosophical trend in nursing practice (Bevis, 1982) and was at the core of the degree course in nursing I undertook at Leeds Polytechnic between 1974 and 1978.

Following qualification, I worked in clinical practice and education at a time when patient-centred care was fostered through the development of the *Nursing Process* (McFarlane and Castledine, 1982), *Nursing Models* (Aggleton and Chalmers, 1986) and later *Primary Nursing* (Ersser and Tutton, 1991). The nursing process places the patient at the centre of care and encourages the nurse, in collaboration with the patient, to identify systematically his or her problems and needs and, through goal setting, plan, implement and evaluate care. Nursing models provide frameworks with which to assess patients and plan individualised care. Primary nursing is a means of organising work

which gives named nurses specific responsibility and accountability for co-ordinating care.

These approaches to care have been and are actively encouraged by various influential nursing bodies. For instance, the nursing process was advocated by the General Nursing Council (General Nursing Council, 1977) and was perceived to *provide a unifying thread for the study of patient care and a helpful framework for nursing practice.* Similarly, in more recent times, influence has been brought to bear on the acceptance of nursing models and primary nursing following William Waldegrave's (Secretary of State for Health) announcement of a £3.2 million award for the establishment of Nursing Development Units. These units have functioned as exploratory pilot sites for the development of new approaches to the delivery of care and have focused in part on the use of nursing models and primary nursing (Cole and Vaughan, 1994). Such approaches represent a radical change in nursing culture, replacing task-oriented methods of organising nursing work with more patient-centred care. In the literature it is referred to as the "new nursing" ideology (Beardshaw and Robinson, 1990).

As a staff nurse in clinical practice I subscribed to these new approaches to care. My degree studies had taught me to be a critical thinker and inspired me to be highly committed to the development of nursing practice. I worked in a variety of clinical settings including respiratory medicine, gynaecology, intensive care and cardiac care, but often felt frustrated because the ideas I had developed at college were rarely observed in practice. Two years after qualifying, I was appointed as the charge nurse of a general medical ward and for the first time felt able to influence directly the delivery of patient care. I enjoyed my key role in the multidisciplinary team, being fortunate enough to be supported by a team of excellent staff nurses who were keen to develop practice and had bonded together in friendship which extended beyond the confines of the ward. Together we changed the way in which the ward was run by drawing on the ideas of the nursing process. At the time of implementation this radical way of giving care required a complete re-organisation of the work on the ward. Instead of nurses being given individual tasks to perform (e.g. observations, drug rounds, dressings), the ward was divided into geographical areas and each staff nurse became responsible for ensuring that the patients in her area received patient care which met their individual needs. These innovative changes at ward level were viewed positively by the hospital nursing management and I was later invited to become a *Nursing Process Co-ordinator* within the hospital, which involved working with other charge nurses wishing to make similar changes in their ward organisation and patient care.

Thus far it can be seen that I was viewed within the hospital as an innovator. However, this kind of development in nursing has not been accepted universally. Whilst influential bodies might have been advocating such new approaches to nursing, their implementation nationally was not encouraged easily (Hayward, 1986) , being viewed by some simply as a strategy for professionalisation (Walton, 1986). The professional status of nursing had been debated long before the nursing process debate. However, its emergence as a new approach to patient care which clearly defined the nurse's role nonetheless served to crystallise issues such as the independent role of the nurse practitioner (Walton, 1986). In particular the new approach raised concerns amongst medics about the shifting roles, responsibilities and relationships. As a clinical nurse, I was fully aware of the powerful role medics played in hospital life and as an educated woman, I resented the inequalities and lack of democracy within the health care team that prevailed. As a feminist I was interested in the professionalisation of nursing but felt the need for a new type of professional. I supported Schon's (1983) belief that there was a crisis in professional knowledge and related the emergence of nursing to the suggestion that awareness of uncertainty, complexity, instability, uniqueness and value conflict had led to the emergence of a professional pluralism. I rejected the dominance of technical rationality on which medicine so heavily relied but whilst wanting nursing to contribute new ideas to health care practice, I firmly believed that as a profession it should not attempt to control knowledge in the manner of traditional professions. On the contrary, I supported the view that nurses needed to become otherwise expert in sharing knowledge with lay people in a more open, humane and compassionate way (Schrock, 1987) and was thus more attracted to the notion of empowering patients than empowering nurses (Salvage, 1992).

My personal involvement with lay participation in care emerged not only through an interest in individualised patient care but also from a concern that, rather than focusing on treatment of illness, nurses could offer an important contribution to health care practice by preventing illness and promoting health (Smith, 1979). Whilst innovators in nursing had been concerned mainly with individualised patient care in the early nineteen eighties, towards the end of the decade, attention focused on the nurse's role in health promotion. It has been suggested that during the nineteen eighties elementary existential principles were affiliated to the basic humanism philosophy which gave patients freedom of choice in health care (Inglesby, 1992). Lay participation in care is very much concerned with freedom of choice in health care and as argued earlier has long been recognised as a major thread in health promotion (Kickbusch, 1981).

My interest in health promotion developed once I left hospital and worked in a local school of nursing. In 1982 I became a mother and wanted a job with more regular hours. Teaching had always interested me and as a staff nurse I helped establish teaching programmes on the various wards where I worked. I was frequently invited to give sessions in the school of nursing attached to the hospital. Whilst no longer directly associated with practice I remained interested in new concepts and ideas in nursing. I was keen to get involved in the curriculum changes which the statutory bodies identified as being important in meeting the future health needs in society (United Kingdom Central Council for Nursing, 1986). More specifically I was given the role of introducing a new component of health education within the curriculum of basic learners.

From a humanitarian perspective, I fully supported the developments in nurse education (United Kingdom Central Council for Nursing, 1986) and later in nursing practice (Department of Health Nursing Division, 1989) which emphasised the importance of health education and health promotion. In my own teaching I recognised the limitations of the traditional medical model of cure in dealing with current health problems in society, for example those associated with the ageing population, unhealthy lifestyle, mental health and environmental hazards. I felt committed to illness prevention and health promotion (Department of Health and Social Security, 1976). However, I was aware of the controversial debates concerning the meaning of health education and health promotion (Baric, 1985) and endeavoured in my role as a nurse tutor to share these ideas with my students. It was during this time that I became interested in the notion of patient empowerment and lay participation in care. Having enrolled part time for an MSc in Nursing, I chose to evaluate formally the curriculum changes being developed which included the introduction and integration of health education, communication, sociology and psychology teaching.

My MSc thesis (Meyer, 1986) left me acutely aware that it is not sufficient to make curricular changes without addressing the more influential pressures of clinical practice. I was therefore delighted to be given the opportunity to register for my PhD and study such an important part of health promotion, namely lay participation in care in the reality of practice through the use of action research. I subscribed to the "new nursing" ideology (Beardshaw and Robinson, 1990) which emphasised the clinical role of nurse as care giver and believed that the development of the nurse as health promoter would not only improve patient care but also enhance the role of the nurse within the health care team. Whilst my interest in health promotion continues I have more recently become involved in the teaching of communication skills to a range of health professionals. I perceive good communication to be central not only for lay-professional relations but

also inter and intraprofessional care. In combining this teaching with further research I hope to play an effective role in fostering collaborative and democratic practices.

From the above it can be seen that throughout my career I have not only been interested in, but have participated in change. I believe that through these experiences I have developed some personal characteristics which support me in my role as an action researcher. At school I was recognised as a leader and team player, frequently being voted by my colleagues as form captain and holding a variety of school offices related to house and sport activities. At the Polytechnic I was one of thirteen students pioneering a new four year course at Leeds Polytechnic leading to BSc Nursing. As a degree student I had opportunities to learn about topics that other nurses had not been taught and this may well account for my interest in new developments in nursing. Being part of a new course also probably affected the way in which I learnt to deal with people. Whilst enjoying both the dual life of a student and of a nurse, it was sometimes hard to feel completely accepted in either role by colleagues in both the hospital and academic settings. In the nineteen seventies I was often made to feel that degree nurses were incompetent practitioners and that nursing was not worthy of academic study. In learning to deal with other people's stereotypes of what a degree nurse should or should not be, I gained confidence in my interpersonal dealings with others. This was to continue even after qualification when I found myself to be the first degree nurse working in the hospital. To promote integration I kept a low profile in respect of my academic training, but as a qualified practitioner I was nonetheless perceived to be progressive in my thinking and valued for my commitment to teaching and sharing knowledge. I mention this because I believe it explains some of the personal qualities I had to draw on whilst acting as an action researcher and also may help to identify some of the differences in understanding between myself and some of the participants in the study.

In summary my main interests remain in humanism and equality, not only between professionals and lay people but also inter and intraprofessionally. Given that both these concepts are central to lay participation in care and action research, it is not surprising that both captivated my interest. My career has given me some strengths in innovation, facilitation, leadership and interpersonal communication. On reflection my weakness is probably an overabundance of enthusiasm for nursing whilst others may not have had chance to develop their thinking on similar lines. For some such enthusiasm is a source of inspiration, but for others I suspect it is overwhelming. Whilst I have always tried to work as a team player, recognising and valuing other people's perspectives, the fact that I appear to have been working towards changes that have eventually been supported by professional and statutory bodies means that to some I may have appeared

as threatening. For instance, during the late nineteen eighties, at the time of the action research study, lay participation in care may not have been fully supported as an initiative in health care practice, but it is clearly on the agenda today. In *"Vision for the Future"* document produced by the Department of Health it clearly states:

> *"The future imperative for nursing, midwifery and health visiting must be to work in partnership with other professionals, users of services and their carers. This participation will improve the general health and life expectancy of the whole population. The philosophy of nursing is in accord with this goal and with the aims set out in Caring* for People *and* Health of the Nation. *The end result of these new initiatives will be an understanding of each individual, and a desire to participate with them in their health care in a way that preserves their dignity".*
> (Department of Health, 1993b, p.4)

What began as a personal interest for me in individualised patient care later becoming focused on lay participation in care, now enjoys a wider acceptance within the profession supported by government.

I hope that the above account gives the reader sufficient background information about my own values and beliefs inherent in my approach to this action research study. My interest in humanism, equality and change are clearly rooted in my family background, education and career and I believe influenced my practice. Thus having related the rationale for the study to both the literature and my personal interests, the following section describes the various stages of the study.

NEGOTIATION: FEBRUARY - JULY 1988

As argued by Simons (1985), fundamental to collaborative research is the need for the researcher to be seen as an "insider". Therefore I decided to approach a hospital where I had previously worked in clinical practice for several years so that the participants could realistically choose whether or not they wished to include me in their multidisciplinary team to facilitate and help monitor the introduction of lay participation in care. Although I had not worked in the hospital for five years, many of the charge nurses, clinical nurse managers and senior medics remained in post and those I approached to participate in the study had either worked directly with me, had known me in the past or had, at least, access to some information about me on which to base their decision. It is interesting to note that, during the period of negotiation, a hospital porter greeted me in a lift with a question as to whether I had recently had some time off! He was rather surprised to learn that in the intervening period I had a child who was of

school age! For some I was perceived as an "insider" but, as the thesis reveals, there were limitations in the role I played as researcher-facilitator.

The negotiation stage began in February, lasted six months and involved a total of fifty two interviews (nurse managers, charge nurses and consultants). Chapter 5 explores this stage of the research in more depth and Chapter 10 discusses the methodological issues of ensuring willing participation in this type of research. During the negotiation stage three wards were identified as being suitable for the study on the basis of mutual selection. One ward was finally selected after I had worked there for a week to establish the whole of the multidisciplinary team's interest in taking part in the study. Originally I had anticipated working on two wards for six months and had wanted to compare the two as case studies. However, as very little change occurred on the first ward after six months, I decided to remain on the ward to record the process of change in more detail.

Having chosen the ward, ethical clearance was obtained from the Chairman of the Ethical Committee, with both ward consultants giving their signatures of support for the research to take place in the hospital. I was given an honorary contract by the health authority to work as a specialist nurse in research and was provided with a base from which to work as well as being given open access to the facilities of the hospital.

During the negotiation stage the charge nurse of the selected ward decided that I should wear a uniform which would differentiate me from other staff on the ward. I felt that the uniform helped in my acceptance as a member of staff by the multidisciplinary team, although on occasions agency staff working on the ward were confused as to my role, assuming me to be one of them. Later in the research, I tended to wear my uniform less and less as my attendance at meetings did not require it and contact with patients diminished. Issues of uniform have been raised in other clinical studies where a researcher has worked alongside a multidisciplinary team (James, 1984). Interestingly, whilst James began her participant observation study wearing a uniform which differentiated her as a researcher, later in the study, she found herself "going native", to the extent of wearing a staff nurse uniform which denoted her more as "one of the team" (James, 1984).

The end of the negotiation stage was marked by me feeding back the outcome to all those who were initially interviewed in the hospital (n=52). Considerable interest was shown towards the project and it was important to keep people informed.

Background detail of the chosen ward

Action research is often written as a single case study and it is not possible to generalise directly the findings to the wider population. Instead it is important to give rich contextual detail of the case under study in order that the reader can best judge the relevance of the findings in relation to their own practice situation. This section gives details of the hospital, ward and climate in which the study occurred.

Hospital

The hospital itself lies in a built up area of outer London. It is situated on a busy main road and serves a mixed racial population. Many of the older inhabitants in the catchment area have lived there all their lives and have either struggled to maintain their own small businesses in an ever increasing competitive world, are employees of the hospital itself, are employed in local light industry, have retired or have become unemployed. Their families have tended to move away, leaving many people (especially the elderly) living alone. Whilst the hospital itself is dominated by a modern tower block, much of the surrounding housing is considerably older. Property has been developed by the younger and more affluent population who tend to travel daily into the centre of London to work. The client population of the hospital is changing, partially due to demographic changes and partially due to the more affluent seeking private health care available following more than a decade of Conservative politics. As with most areas of London there are pockets of long established wealth and relative stability, but a large proportion of the population is sufficiently mobile that half of the homes in some areas change occupants every year. There is also a large number of immigrant workers and ethnic minority families in the area which adds a rich cultural mix, along with the thousands of tourists who visit the capital city every year and find accommodation in the area.

The hospital is a modern major London teaching hospital with 800 beds, providing a comprehensive service to its local people and acting as a regional centre of excellence for certain specialities. It deals with all types of illness and compared with national figures, has a low death rate for respiratory disease and a high death rate for cancer, accidental injury and poisoning. Notably there is a higher than average demand for its mental health services and for its services for drug misusers, people with sexually transmitted diseases and family planning. In the past seven years the impact of AIDS has had a major bearing on the planning of local health and social services in the region.

Ward

The ward is best described as a mixed general ward being specially interested in gastrointestinal medicine, alcohol abuse and AIDS. It is physically located in the tower block of the hospital and has twenty six beds which are laid out in bays of four or six or within single rooms.

At the time of the study the charge nurse of the ward had a wealth of nursing experience having been qualified since 1971 and having worked in thirteen different hospitals. She had been in post for eight years as the manager of the ward and had previously worked in the hospital on night duty. The charge nurse was supported by ten qualified nurses, one part-time auxiliary and one part time ward clerk. Most of the qualified nurses working on the ward tended to stay in post for six months to one year before moving on to a different speciality. The ward was usually allocated eight learners, about 50% of whom were on their first ward experience and requiring more support than the other more senior learners. The charge nurse was expected to maintain an internal rotation on night duty and had to rely regularly on agency and bank nurses since nurse recruitment within the hospital was a problem. This was in line with staffing difficulties elsewhere in London.

The two ward consultants were well established, one having been in post for twenty three years and the other for thirteen years. The senior and junior registrars, of which there was one of each at any one time, tended to stay in post for one to two years, whereas the two allocated house officers rotated to different wards every three months.

The paramedics associated with the ward included a dietician, occupational therapist, pharmacist, physiotherapist, social worker and speech therapist and were usually on a three monthly rotation in the hospital.

As mentioned previously several of the nursing and medical staff knew me from my previous work in the hospital. However, the paramedical staff were less familiar with me as the majority had trained in other hospitals.

Having described the hospital and ward, the next section describes the general climate in the health service at the time of the study.

Climate

During the period of the study the hospital was under pressure to improve efficiency and service to patients whilst keeping within a reducing budget. It was also

during the post Griffiths Report (1983) turmoil when major changes were occurring in the National Health Service and, in particular, senior nurses were feeling very much under threat (Robinson et al., 1989). Furthermore nurses were being regraded and, at all levels, they were being asked to review their job descriptions, roles and responsibilities, perhaps for the first time. Subsequently they were feeling undervalued, with many nurses going to appeal. One senior nurse in the study commented on the effect of all the changes:

> *"Everything was taken personally....People saw themselves being graded for what they were actually doing and that was erroneous and it has taken quite a long time for people to recover from that. I think that had the biggest impact on the hospital throughout the year."*
> (Nurse: N15a(E)p6)

In addition, Project 2000 was on the agenda and participants were feeling apprehensive as to where they were going to fit into this major educational reform. Within the hospital the workload had generally increased, with the fixed establishment not accommodating the increase in demand for care. A local hospital had been closed and posts were being "ring-fenced" for the future amalgamation of staff from the two separate sites, which represented a mixing of two different cultures. The ward clerks were in the middle of a two year dispute and working to rule. The cleaning had gone "out to tender" and was proving an inadequate service and the staff were having to contend with support services trying in vain to run at a five day per week. Furthermore during this time, the front entrance was inaccessible due to lengthy refurbishment, extensive work was being done on the lift system and the canteen was closed as a health hazard. Wards were being closed for redecoration but then, due to lack of funds, not reopening. Added to which some cladding had fallen off the back of the hospital and a fire had damaged another part of the building. Again money was not available for structural repairs. Thus morale was extremely low, with people adjusting to new ideas, concepts and roles and working under less than adequate conditions. Pressure was on staff to reduce waiting lists whilst at the same time there was a movement towards trust status. A top down approach to change was very much in force and it left health professionals with a sense of helplessness. As one senior medic said:

> *"Oh, I think morale is something very important. I think it's utterly depressing - the repeated problems of the Health Service - lack of knowledge about the future , the uncertainty about the future at all levels, be it loss of junior staff, be it the question of hospitals being privatised, increasing shortage of school leavers, the long term prospects....I see no way in which the Health Service is responding, or*

the Government is responding to the challenge. It hasn't been aired at all. It's so close to being upon us that I don't see that we are going to be able to ride the storm unless something is done fairly soon about it."
(Medic: M2(E)p11)

Thus the picture set as the context for this case study should be born in mind when one looks at what occurred during the year of study. Whilst one might question the choice of ward for innovating change, I believe the environment was no different to many other hospital environments at that point in history. Given that so much change was being made from above, it could be argued that a bottom up approach to change might have empowered staff, including participants, to cope better with their situation. By taking a non-directive facilitative role, I hoped not to force my ideas on the participants but to enable them to examine their practice and reflect upon new ways of giving care, which would be more in line with future health care needs. Given the flux of change in the health care system, I believe the study throws light on many important issues which need to be considered by policy makers interested in changing practice.

ORIENTATION: AUGUST 1988

During this time I began to orientate myself on the ward as an "insider" and thus develop my role as an action researcher. I spent time working alongside the staff, attending meetings and generally "hanging about" listening to people's stories concerning the work of the ward. Schatzman and Strauss refer to this part of field work as "mapping" and describe it as the:

"first reliable and extensive (not intensive) look at things, persons, and activities that constitute the site".
(Schatzman and Strauss, 1973)

I started to record field notes daily, and began a profile of the ward noting details about staff as well as the types of patients admitted and the general routines of the ward. I also provided each participant with a copy of my research proposal and began to discuss informally ways in which the project could be developed and monitored. In an attempt to get to know the environment, I offered myself as a pair of hands to work on the ward and, although not strictly in my remit as a researcher, this did enable me to gain some interesting insights into the workings of the ward with regard to lay participation in care. One field note records such an incident:

"When I asked staff nurse if I could help, she said I could "do" the lady in F6. I approached the patient who was terminally ill and constantly being visited by relatives who were sat around the bed. I asked her if she wanted a wash and she said "no". Her relatives explained that she was exhausted and wanted to rest. The auxiliary working in the bay came over and tried to persuade the patient to have the bed bath offered. She said that it would be better to have the wash, then afterwards she could go to sleep and be bothered no longer. I suggested to the auxiliary that the patient and relatives didn't want this, so perhaps we should leave her to rest. The auxiliary said 'whatever you say' and we both left the bedside. I noticed 15 minutes later that the auxiliary was washing the patient."
(Field Notes: R(F)p10/11)

This incident remains in my mind because it summarised the routine, task oriented nature of the work being carried out on the ward and introduced me to the idea that relatives had a role in trying to protect patients from staff. It also made me sharply aware of my potential lack of influence on changing practice. Whilst I was endeavouring to gain acceptance as an "insider" and perhaps through that influence change, I had no formal position of power and, as such, would have to rely on others to determine not only how care would be given but also the degree to which participants would adhere to the principles of lay participation in care. Acceptance as an "insider" involved getting to know participants well and gaining their trust, in order that they might feel able to share their ways of seeing the world and possibly engage more in the ideas of the project. This suggested a sense of manipulation, on the part of the researcher, which is an issue explored later in Chapter 10.

MAIN STUDY: SEPTEMBER 1988 - AUGUST 1989

Initial data collection

The main data collection began in September. During this month I wanted to establish what health professionals and lay people understood by the term "lay participation in care" and identify ways in which their ideas could be facilitated in practice. I also wanted to describe the ward and use these data as a baseline to see if change occurred over time.

To this end I interviewed all the multidisciplinary team members to ascertain how they felt about lay participation in care and what they thought would be the likely difficulties of putting it into practice on the ward. Questions also centred around what changes they would like to make to facilitate lay participation in care and whether any

particular patients would be more or less suited to this type of care. Finally, participants were asked to reflect on their own personal experiences of being in hospital as a patient or as a visitor as this might give them other insights into the needs of lay people in hospital. These data were supplemented by giving all interviewees and the learners on the ward a modified "Patient and Family Participation in Nursing Care Scale" (Brooking, 1986) to complete and return me. This was done not only to support data gathered at interview but also as part of the education process for staff to think again about the ideas of lay participation in care.

During the first month of data collection I had hoped, perhaps ambitiously, to be able to interview patients and their family and friends to hear their views on lay participation in care and to collect suggestions for change in practice. This did not prove possible for several reasons. I had planned to interview people in their own homes as conformity may occur in hospital. However, this method proved too time consuming and I felt conscious of the need to complete this part of the data collection quickly in order to draw up a plan of action to direct the change in practice. Instead I chose to interview patients and their family and friends on the ward, but problems occurred with this approach. During a two week period, a total of thirty seven patients were nursed on the ward but only four were considered suitable for interview and two of these had no close family and friends with whom the concept could be explored further.

I therefore decided to base the decisions for changing practice on the interviews from the multidisciplinary team alone. This was not a comfortable decision given that the study was about *lay* participation in care. To overcome the problem, it was decided that once lay participation in care was actually being offered on the ward, then the lay views and wishes could be incorporated into the project design as part of a formative evaluation. It could be argued that this method was more appropriate on the basis of it being immoral to ask patients what they would like in the way of care, when the ward was not necessarily in a position to deliver. Furthermore, as will be seen from the professional responses, theoretical comments made at interview may again differ from what people are actually prepared and/or able to do when confronted with a concept in reality.

Apart from gathering data to establish the professionals' perceptions of lay participation in care and determine what change was needed on the ward, I also wanted to describe the ward and use these data as a baseline to see if change occurred over time. A variety of measures were used to do this.

First, the ward was assessed as a learning environment using the Ward Learning Environment Rating Scale (Fretwell, 1982). This was completed by all learners joining the ward throughout the period of the study and was therefore a study of change over time. Given that the focus of the study was about changing the professional's role to an "educative and supportive" role rather than a "doing" role in order to facilitate lay participation in care, it was thought that changes might occur in the learning environment during the period of the study. During the interview, participants identified the need for more teaching on the ward which led to a new teaching programme being introduced. It therefore seemed appropriate to measure this facet of the ward's culture to supplement data from the field notes and interviews.

Second, the ward was assessed to observe the extent to which the nursing process, which involves the patient in planning and evaluating care, was being applied. As the concept of lay participation in care was being developed on the ward, it was considered likely that the scores of the Nursing Process Measurement Scale (Brooking, 1986) might increase and that this would be another useful facet of the ward's culture to examine. Again these data were gathered over time as new nursing staff (qualified and learners) joined the ward.

Third, the ward was assessed for change using the quality assurance measure, Qualpacs (Wandelt and Ager, 1976). Throughout the research, daily field notes were kept so that the process of change could also be monitored. In particular these field notes focused at the beginning and end of the study on the health professionals discussion of lay participation in care in ward reports, ward rounds and multidisciplinary meetings. A description of the instruments used is given in Chapter 5 where the methodology is addressed in more detail.

Action-reflection cycles

By the end of October, I had gathered sufficient data from the participants to begin the process of feeding back, essential to any action research study. The initial interviews with the multidisciplinary team threw up many issues that could not have been anticipated. In particular, difficulties in communication within the multidisciplinary team and the poor organisation of care were highlighted. It was suggested by the participants that before patients and their family and friends could be invited to participate more, there should be more participation amongst the health care team itself. Nurses complained that they often did not know what patients had been told by other health professionals and medics complained that nurses did not attend ward rounds and were passing on inaccurate information at report times. To illustrate this, one nurse said:

"I think on the whole both doctors and nurses are terrible at giving out information to relatives and patients, and I think that I would like to see the nursing staff being able to give out a lot more information and being able to talk through it with the relatives rather than the doctors coming round on ward rounds and in five minutes telling so and so what's wrong with them or what they're going to do. But I also think we're kept in the dark until the last minute and then we're expected, you know, to answer the relative's questions and we don't know what's going on."
(Nurse: N5(I)p5/6)

I began by establishing regular meetings on the ward to discuss issues raised and plan action. Clearly this opened up channels of communication that had not occurred before on the ward and were to have major implications for ward practice, as the story will reveal. Multidisciplinary team meetings took place once a week to discuss the project ideas. These meetings took place before another multidisciplinary team meeting to discuss the patients' social problems, which ensured good attendance. Unfortunately one of the consultants was not able to attend any of these meetings due to an out-patients clinic and he had to rely on the feedback sheets given out after each meeting and on individual contact with me. This may well have interfered with his ability to become more involved in the project ideas. All the other medics attended together with a nurse representative (usually charge nurse), the dietician, occupational therapist, pharmacist, physiotherapist, social worker and me. The speech therapists decided not to send a representative as they organised care on the basis of general referrals to their department and so no one person was allocated to deal with problems on particular wards. Because only one nurse representative attended the multidisciplinary meetings, it was agreed that there would be a weekly update for the nurses who could not attend, which would give them an opportunity to contribute their ideas to the project. These meetings usually occurred after the lunch time handover report whilst patients were resting, but sometimes had to be cancelled because of the demands of the ward or because I was not available. On some occasions they occurred twice a week if staff returned from days off and had not been able to attend a previous meeting. Appendix II summarises the feedback and planning meetings that took place on the ward.

During the main part of the study (September 1988 - August 1989) there were twenty six multidisciplinary team meetings, twenty seven qualified nurse meetings and twenty two other meetings where I met various members of the nursing or medical team (either with or without the charge nurse) to feedback issues relating to the project. On

twenty other occasions (between September and June) I met with the charge nurse alone to discuss the project formally. This mainly occurred towards the end of the project, after a new charge nurse had been assigned to the ward when the nature of my facilitative role altered. It was on the basis of these meetings that the action-reflection cycles were planned and monitored.

Action-reflection cycles are central to any action research study and can be described as the collaborative spirals of planning, acting, observing, reflecting and re-planning that occur between the researcher and participants (Kemmis and McTaggart, 1982). However, this research study did not follow a prescriptive model of action research but allowed for more spontaneity and creativity as advocated by McNiff (1988). Thus the action-reflection cycles were not determined in advance of the project but emerged during the passage of time and have been used in retrospect to describe the events that occurred.

Three main action-reflection cycles emerged from the project. The first cycle was concerned with exploring how lay participation in care might be developed within the context of a ward environment. The second cycle was concerned with the need to explore multidisciplinary communication on the ward. As mentioned earlier it was suggested that lay participation in care could not be offered until there was more interaction between the health professionals. The third cycle looked at the need to fundamentally reorganise the working practices on the ward to allow for a more individualised approach to care. The two latter cycles were identified by participants as needing to be addressed before lay participation in care could be introduced in practice.

Cycle 1: reorganising the work of the ward

I found myself in the second and third month of the study being very much concerned with facilitating new ways of working. Through the weekly meetings a policy of lay participation in care (Appendix III) was drawn up and the discussion centred on how the policy might be implemented. Several nurses on the ward wanted to reorganise their work by introducing a modified form of primary nursing (key nurse system). It was suggested that the ward could be divided up into small areas and that each qualified nurse could be given responsibility for the patients in that geographical area. This would enable participants to establish a more meaningful relationship with the patients so that the ideas of participation in care could be explored with them and their family and friends. They argued that no nurse could possibly get to know all the patients on the ward in sufficient detail to offer such an individualised form of nursing. Once it was agreed by the nurses, a policy on the key nurse system (Appendix IV) was presented to

the rest of the multidisciplinary team for comment. In this way the new system of patient care was considered and established jointly with the multidisciplinary team.

Various "spin-off spirals" emerged from this action-reflection cycle of introducing new working practices (the key nurse system). "Spin-off spirals" naturally occur in generative action research and allow many different problems to be addressed at the same time without loosing sight of the main issue (McNiff, 1988). In the study the responsibility for allocated patients brought with it the realisation that written care planning was a weak area on the ward. Previously, care plans had been written as a routine on the ward, but allocation of responsibility for specific patients made the qualified staff look more closely at their practice. The staff nurses commented that they wanted to introduce the hospital's new care plans, but were being given little guidance and support with this. I had been a nursing process co-ordinator in the past and had been asked by the hospital to do some consultancy work on other wards helping them use models of nursing in their practice. It seemed appropriate to offer these skills to the ward. I organised teaching sessions on care planning and when invited I worked with nurses on an individual basis in developing their skills.

In general the nurses became enthusiastic for change. They appeared to welcome the opportunity to make suggestions for change and their ideas were fed into the ward policies, already mentioned. One staff nurse in particular took it upon herself to set up a teaching programme on the ward for staff and learners and another staff nurse organised a more formal system of mentorship for the learners which linked into the key nurse system. Another initiative or "spin-off spiral" was a change in the reporting system on the ward. The act of reporting had always occurred on the ward at the central nursing station but it was constantly being interrupted by queries and telephone calls. A decision was taken to have the report given in a room off the ward and to use it as a time to talk in more depth about the patients and their problems and needs. Later it developed into a "care plan round" with care being discussed more frequently at the bedside.

However, despite the good intentions to change the way care was organised on the ward, the initiatives floundered. This was largely due to the charge nurse not becoming actively involved in directing the changes to be made. She often said that the nurses could do what they wanted to but her experience meant she did not hold out much hope for their success. Moreover the charge nurse was adamant that any change should not involve her in more work, as she already felt overloaded with the variety of tasks she was being expected to perform (e.g. writing new learning objectives for the learners, new telephone system to master, possibility of holding her own budget). The staff complained

frequently about the charge nurse's negative attitude to change and wished that she would act more enthusiastically as leader. As the project moved on this issue became an increasing problem and a sense of frustration set in with the participants. This is illustrated in the comment made about the charge nurse by a nurse at interview:

> *"She was all for the project but when it was actually going ahead, she kept stopping us in our tracks, finding reasons why 'No, you shouldn't do this, You shouldn't do that'. So it was very difficult. If you have a problem with a patient or with a system of key nursing, she didn't have an answer for it. She blamed it on us - it was the Staff Nurse not making it work whereas she is the facilitator - she is the ward sister, she should have been making it work and asking the question "Why isn't it working?" and sit down and talk about it. That wasn't going on."*
> (Nurse: N1(E)p13)

This lack of enthusiastic leadership posed a particular problem for me in my role as facilitator-researcher. At times I wondered if I should have been more pro-active in directing the change. I very much worked from the premise that the initiative and direction had to come from the participants. I was conscious that my role was temporary and that the participants had to own the project ideas in order that the innovation would be sustained after I had gone. I was also conscious that it was not my ward and that I would make myself an unwelcome guest if I tried to take a more directive role. However, without an enthusiastic leader at the helm, initiatives were not sustained and enthusiasm dwindled as participants found the old system of nursing was being allowed to run in tandem with the new. The two together were incompatible. For instance, the "off duty" rota was not being written to support the key nurse system and so the qualified staff were finding that they were rarely able to work with their key patients. As a result some key nurses were not on top of what was happening to their patients and so the old system whereby the charge nurse of the shift would make independent decisions about patient care started to occur. Once it became evident that nurses were not bothering to take on their new responsibilities and were not being held to account for this, other nurses questioned why they should bother to put themselves out in a team that was not pursuing the same goal.

Cycle 2: multidisciplinary communication

Another important action-reflection cycle concerned the lack of interaction between the health care professionals themselves. The establishment of feedback and planning meetings probably went some way towards helping to improve multidisciplinary

communication. Prior to this there had been no regular multidisciplinary meetings where ward practice was discussed. The consultants tended to visit the ward for their formal ward rounds, but there was little other contact with the charge nurse. Ward practice was seen to be the business of the charge nurse, but she was reluctant to change things in case the consultants did not approve of such changes. As a result patterns of work continued without allowing opportunity for reflection and change. However, the feedback and planning meetings allowed other health professionals to feel more involved with the ward. For example despite it being a general medical ward with a gastrointestinal interest, the dietician only really came into contact with the ward through patient referrals and the pharmacist also played a distant role prior to the project. But during the project it was felt that communication amongst the team did improve even though it gave rise to other issues that unfortunately were not resolved. The opportunity for reflection at the meetings was severely limited due to lack of time. There was also a problem with medical, and in particular consultant, domination within the multidisciplinary team. This domination seemed to be fuelled as much by the other multidisciplinary team members, as it was demanded by the senior medics. It transpired that nurses, paramedics and junior medics were reluctant to express their views in meetings in front of those they perceived to be their seniors. For instance, when this was brought up as an issue one of the paramedics explained:

> *"I think people are just slightly intimidated, they don't want to say what they really feel in front of somebody who might be in a position to criticise them, or say well why do you think that? I don't think that. You don't want to get into a confrontation situation with your superiors I suppose."*
> (Paramedic: P13(E)p8/9)

This lack of engagement for fear that expressing opinions would lead to criticism created an unequal balance of power within the team. One might reflect on gender issues as being partly responsible for this but another factor is likely to be transience. Paramedics and junior medics were rarely allocated to work on the ward for longer than three months. It was therefore very difficult for them to feel that they belonged to the team and had a valuable contribution to make. Whilst the qualified nurses on the ward stayed for longer, it was only the senior qualified nurses who had contact with the senior medics through ward rounds and occasional attendance at meetings. Given this lack of contact and lack of confidence in expression, it was not surprising that there was poor multidisciplinary communication.

Apart from the weekly multidisciplinary team meetings, there were three other "spin-off spirals" connected to the main action-reflection cycle of trying to improve multidisciplinary communication. First, an orientation handout was written for new staff when it became apparent that there was little or no handover from the previous staff and that their roles and responsibilities were not always explained. Moreover new house officers found it difficult to engage in the project ideas in the early months of being on the ward, which highlighted issues about their orientation and management as well. The second "spin-off spiral" was the introduction of a multidisciplinary communication sheet which was placed in the nursing kardex of each patient for written messages to be shared amongst the team and the third "spin-off spiral" was an exploration of how the community nurses felt about lay participation in care in hospital. This was done to promote good liaison between the hospital and the community by both informing them about the innovation and also ascertaining the community perspective on what might better prepare patients for their discharge from hospital.

Cycle 3: lay participation in care

It seemed as if the first action-reflection cycle of introducing lay participation in care could not start to be addressed until some of the issues about ward organisation and multidisciplinary communication had been addressed. As the thesis will reveal, the professionals appeared to have a limited understanding of the concept of lay participation in care and to some degree perceived it as a threat to their professional practice. Difficulties arose when consideration was given to how the policy might be put into practice. The first major problem arose when the consultant expressed concern that he could be held responsible if anything went wrong with the new approach to care. This concern was also expressed by the charge nurse in her initial interview when asked to think of disadvantages with this type of care:

> *"Well the pressure that's on them to do it and the fact that they're not trained, they may not be suitable to be trained and if they make a mistake then who's responsible? Depends what sort of care they're doing I suppose. I'm worried about them making mistakes in the ward situation, who's responsible for that?"*
> (Nurse: N0(I)p4)

In dealing with the problem, the hospital solicitor was approached who advised that the professional bodies should be consulted. Unfortunately this was at the time of regrading for nurses and the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC) and the Royal College of Nursing (RCN) were inundated with other queries. As a result the project was set back by two months until a reply from

the Director for Professional Conduct at the UKCC indicated that "Provided that it was done correctly and with due care I see no problems on the professional liability front". He advised the health authority should cover these proposed developments by the preparation of a written statement (Appendix V). Given the increase in legal suits against the medical profession, it was understandable that this concern over professional liability was an issue for the medics. However, it represented a conservatism that pervaded and hindered the development of the project. Conversely it could be argued that lay participation in care was already in place and being actively encouraged by many different patient groups (e.g. diabetic and renal patients) and that all the project was trying to do was to systematically offer it to a wider group of patients. Provided the professional codes of conduct were adhered to, there should really have been no reason to question professional liability.

Whilst awaiting replies from the professional bodies, it was decided to spend the time on three other "spin-off spirals" connected to the main action-reflection cycle of introducing lay participation in care. These were to develop resources for patient education, the medicine reminder card system and the introduction of the patient information letter.

First, the need to develop resources for patient education was identified on the basis that lay participation in care required health professionals to move towards a more "educative and supportive" role. Thus links were made with the local health promotion unit and advice sought as to what materials might be useful. The League of Friends provided money which enabled the ward to purchase some books, directories of self help and support groups, a leaflet rack to display the patient education literature, an audio-tape player and some educational cassettes. Self help and voluntary groups and drug companies were also approached for samples of their patient education literature which could be used on the ward. However, the use of the patient education material in practice was delayed because one of the consultants wished to vet the literature in case messages conflicted with their medical advice. The vetting took approximately two months to complete and proved to be quite an arduous task. Interestingly, no leaflets were discarded because they were considered unsuitable. Again, given that this material was freely available to the general public outside the hospital, this could be viewed as another conservative response to what seemed to be viewed as a potential threat to professional practice.

The second "spin-off spiral" to the main action-reflection cycle concerned the development of a system for educating patients better about their medical treatments. For

example at the feedback and planning meetings, the medics aired a concern that patients were being readmitted due to non-compliance with drug taking regimes. It became apparent that no one in the multidisciplinary team was taking responsibility for ensuring that patients knew about their drugs and were competent in taking them prior to discharge. This highlighted once again the lack of patient oriented practice on the ward. In an attempt to address this problem it was decided that the house officers would educate the patients about their drugs and give them a medicine reminder card to monitor their own drug taking whilst in hospital (Appendix VI). A system was established where such education would be reinforced by the nurses on the drug round and patients would be encouraged to monitor their own drug taking after discharge and return to out-patients to give comment on the usefulness of such an approach (Appendix VII). The system was designed by the medics and required them in out-patients' department to complete a simple evaluation form commenting on the use of the medicine reminder cards.

My role was to monitor the system and provide feedback on its progress. Weekly feedback was given to the team on the state of the medicine reminder card system and despite my reports that the system was not being utilised properly, the senior medics stated that they wanted the system to continue as they saw it as a way of improving patient care. However, after seven months only 63 out of 115 (55%) of patients eligible to receive a medicine reminder card had been given one, and only two evaluation forms had been returned (4%). A pattern emerged which indicated that the house officers did not see their role in patient education as a priority. During the first month of being on the ward they were overwhelmed by the usual routine tasks which needed to be done and avoided engagement with the tasks of the project. In the second month, they felt better able to cope with their roles on the ward, had established a relationship with me and were starting to show an interest in the study . In the third and final month of being on the ward they appeared to realise the importance of patient education, having seen patients who came back to out-patients as a result of not taking their drugs properly, and actively started to be committed to the project. However, not long after this commitment there would be a change over of house officers and the cycle would begin again. As one house officer said:

> *"I think it was very difficult to get a grasp of the working of the ward. It takes time. Three months, I think, has been just sufficient for me to feel comfortable now and if I was to stay another 3 months it would be a lot easier ..... I think that has been a big problem in actually making new housemen (sic), I speak for myself, do more. The other small aspect with me personally was a slight feeling of why are we doing all this and who is initiating it and why. But that didn't last*

very long. I mean I recognised from very early on the importance of the concept of a medicine card, if only we had more time to actually put things into practice."
(Medic: M31(E)p3/4)

The medicine reminder card system highlighted many interesting issues relating to the difficulties in changing practice and in particular demonstrated the need for house officers to be guided and better supported in the clinical area. Though the system was not a complete success, the exercise proved to be worthwhile in terms of gaining understanding about the nature and management of medical work.

The third "spin-off spiral" to the main action-reflection cycle concerned the development of a patient information letter which identified the key multidisciplinary staff and invited the patient and their close family and friends to become involved in care on the ward (Appendix VIII). This letter was distributed to patients on the ward by the nursing staff but made very little impact. The nursing staff did not appear to have the skills to be able to sit down with individual patients and identify in what way they might become more involved in care. Simply leaving the letter on patients' lockers was not enough to stimulate involvement. As one nurse said:

"No. It's approaching the relatives really. How to do it, what to say to them. How do you know if they want it (lay participation in care) or not?"
(Nurse: N15(I)p18)

Some nurses felt embarrassed about exploring the concept of lay participation in care with patients in case lay people saw them as trying to off load work. For the few nurses who did engage with lay people in this way, there was a sense of being rebuffed when participation was not wanted, even when the family and friends explained that they saw hospitalisation as a form of respite care. This seemed to indicate a lack of conceptual understanding on the part of the nurses in that refusal by lay people to get involved in care in hospital was seen by the nurses as a failure on their part. This would seem to concur with a manipulation towards compliance rather than a realisation that an active decision had been taken by the lay person and this represented true participation in care (Brearley, 1990).

In my view the best example of true participation in care that occurred during the year of the study involved the case of a 75 year old man who had a thoracic disc lesion. However, others on the team saw their interaction with the patient as failure. He was admitted to hospital suddenly having become immobile from the waist down, and had a

dry cough, indicating a possible primary cancer of the lung and thus a poor prognosis. He desperately wanted to go home. It was as if he had not said good-bye and felt restless over possibly not seeing his home again. A multidisciplinary case conference was called to discuss the possibility of his going home. The case conference took place with the patient and his wife in his single room. Each professional talked honestly about what could and could not be offered to make his discharge home possible and it soon became apparent that much would depend on his wife being able to participate in his care at home. She cautiously agreed to attend physiotherapy to learn more about how she could help him at home. However, in a quiet moment later she questioned whether once home she would be expected to keep him there. She was reassured that this would not be the case. During the following week considerable energy went into arranging services and paving the way for his return home. However, after the weekend, I went onto the ward to discover his key nurse extremely upset because the patient had been angry, withdrawn and tearful. His wife had not been in to visit him and was clearly showing signs of not wanting to participate in care. The key nurse wanted to call a case conference to discuss the matter and above all how to get him home.

I went to see the patient and came away with a completely different picture. He told me he had given the prospect of going home much consideration over the weekend and realised now how impossible it would be for his wife to cope with him there in his present condition and that he felt it was not right to expect her to. He said he had not really thought it through before, but after the case conference realised that what he needed was basic care and that this would best be provided in hospital. After further discussion I returned to the staff nurse and explained how he was now viewing things. She said she felt she had not been asking the right questions and had really only been focusing on the patient and had not been considering the total needs of the family. A few days later the patient died and his wife wrote to the ward, shortly afterwards, expressing her thanks for the individual attention given to both of them. Some of the staff felt they had let the patient down by not getting him home before he died, but I saw it differently. I felt we had helped both the patient and his wife to explore realistically what was possible and together had come to terms with what was the right decision for them. In the past, multidisciplinary case conferences with the patient and relative present had not taken place on the ward and for me this was a good example of lay participation in care in practice.

Challenging inertia

During this time there was a sense that the nurses on the ward would have benefited from a role model showing them how to put the new approach into practice.

They appeared to lack the confidence and skills to explore issues with patients and found patient teaching difficult. On occasions, when invited, I did work with individual nurses and through the qualified nurse meetings started to look at ways in which patients and their family and friends could be more involved in care. However, gradually I realised that not all was going well with the project and questioned if my presence was really wanted on the ward. A sense of frustration had developed amongst the participants as ideas talked about did not seem to be translated into practice. As one participant said:

> *"Because I was quite enthusiastic to begin with and I don't know, but it just seemed as if everyone was hitting their heads against a brick wall from the beginning to the end and just more and more difficulties were coming up - and I began to loose faith, I think, in what you were trying to do anyway."*
> (Nurse: N5(E)p5)

Transience of staff proved to be a major problem throughout the project. I calculated that during the one year period, taking into account the entire multidisciplinary team and the nurse learners who made up a significant part of the workforce, eighty five new staff started on the ward and eighty nine left representing one hundred and seventy four disruptions to the ward dynamics. It was hard to sustain the momentum for change in an unstable workforce, especially when there appeared to be a lack of leadership in managing the change process. I was anxious not to get involved in leading the changes myself and frequently had to remind participants that they had to want the change for themselves as ultimately I would be leaving and the change had to be sufficiently important to maintain itself after I had left the ward.

An example of lack of leadership can be drawn from the field notes. Once the nurses had decided on the key nurse system policy it was thought to be important to inform the rest of the multidisciplinary team as to which nurse was looking after which ward area in order that they might be consulted directly about particular patient problems. Given the frequent changeover of staff and problems (due to internal rotation to night duty requiring nurses to cover for one another), a white board was thought to be useful in communicating to the rest of the team responsibility for patients. I helped the ward to obtain a whiteboard and marked it in such a way that it could easily be altered and updated. However, it was decided that I should not be the person responsible for keeping it updated as I would be leaving the ward sometime in the future and a more long term system needed to be established. At a meeting of qualified nurses it was decided that the charge nurse of the ward should make the alterations on a weekly basis. However, in reality this was not done and as a result no one really knew who was looking after which

patients and the key nurse system floundered. In January the white board had not been updated for several weeks and when pointing out this fact to the charge nurse she commented that over Christmas the ward had been very busy and maintaining the white board had not been her priority:

> *"If you put all the things I have to do into a hat and shook it, writing the board would fall to the bottom as that is the least of my priorities. It's a struggle to just get on with doing the baths, feeding the patients, making the beds."*
> (Field Notes: N0(F)p176)

In reality very little changed in the way that care was organised on the ward. The nurses found it difficult to implement the project ideas for a variety of reasons which are explored in the findings and discussion chapters of the thesis. Suffice it to say that by February I felt I should offer to withdraw from the ward as there appeared to be a lack of commitment to changing practice. On negotiating access to the ward I had said that if at any stage anyone felt that they did not want to continue with the project ideas, I would withdraw and it would be documented as to why this had become necessary. However, one of the factors leading to this decision was a breakdown in communication between the charge nurse and myself. I became very conscious that the charge nurse appeared to be ignoring me on the ward and was cancelling the qualified nurse meetings without consulting me. This led to an embarrassing situation where a staff nurse had not known how to respond to me when I arrived on the ward for a meeting. Field notes recorded this as follows:

> *"Later that day I returned to the ward after report for the Thursday meeting. The charge nurse continued to ignore me and started the routine ward work.. ..... After an embarrassed 5 minutes staff nurse (N14) confronted charge nurse and said are we having a meeting or not. Charge nurse said it had gone 2.30pm and there was far too much to do. Staff nurse objected strongly saying she felt it was important to meet as it was through these meetings that patient care would improve. The scene was an ugly confrontation in public with sister's authority being clearly questioned. I left the ward feeling angry not because there wasn't to be a meeting but because in all this the charge nurse had not even acknowledged me."*
> (Field Notes: R(F)p220)

This situation could not be ignored more particularly because action research depended on the collaboration of the participants. I returned to the ward to speak to the charge nurse about my concern that I did not feel welcome on the ward and that the

project ideas were not being supported. The charge nurse commented that she felt that there were too many meetings taking place on the ward. She resented the way other people's values were being imposed upon her and felt the ward was changing beyond recognition. She did not like the way the staff nurses were questioning her authority and felt that my presence on the ward had been disruptive. She also said that she was unhappy with the research because it had gone on so long and had got nowhere. Too much time she believed was being spent on the key nurse system and not enough time on lay participation in care. Whilst she commented that communication on the ward had improved and she recognised that the staff nurses were keen to get more involved in the ward, she doubted how successful they would be because as mentioned earlier she had tried it all before and got nowhere. Issues around these points were discussed and, whilst the meeting had not been heated or held in anger, I felt resentments had been expressed that could not be ignored and felt the need to offer to withdraw formally from the ward. We decided to go and discuss this with the nursing management with whom I had originally negotiated access to the hospital.

However, withdrawal from the project at this stage did not occur. The other members of the multidisciplinary team expressed a wish for the project to continue and the nursing management suggested that the charge nurse had a responsibility to manage the change. Issues that had arisen were more to do with reluctance to change and given the constant flux of change in the future of the National Health Service, it was suggested that everyone needed to examine their own roles and recognise their own strengths and weaknesses in changing practice. Through this process the charge nurse recognised there were aspects of her job that had changed over the years and in particular she resented the time she now had to spend on management in preference to practical nursing, which she identified as her strength. She acknowledged feeling under increasing pressure over the years and suggested that the project had added to this pressure and brought it to a head. In particular she found the project made her feel very vulnerable because she felt everyone was criticising both her and the way she ran the ward. She found it difficult to relate to me being so enthusiastic when she felt so negative. She identified that she needed more support and had felt very isolated in the past. Discussions centred around how problems in the past had been highlighted but ignored - there was a sense of "sweeping under the carpet" issues that she had raised in the hope that the problems would go away. The nursing management gave a formal commitment to the project ideas and asked the charge nurse to identify what help she would need in the future. The charge nurse commented that it had helped to have these discussions and she would welcome more support of that type in the future. Promises were given that a member of

the nursing management would keep more in touch with the developments on the ward by attending meetings.

For a period of several weeks, the project seemed to move forward in that meetings took place as planned (when the ward was not too busy) and the staff showed more ownership of the project by suggesting that they ran the meetings to discuss the key nurse system and that I ran the meetings to discuss lay participation in care. However, in reality still very little changed. There were disagreements amongst the staff concerning how the key nurse system should be managed. Furthermore there had been several staff changes and not everyone felt able to be responsible for a ward area on their own. Given the constant changes in staff it was hard to implement ideas consistently and at the same time maintain motivation. New members of staff would enter the system at a different level of understanding and without an enthusiastic leader to direct them. Attempts were made to adjust the ideas to suit the new staff and a system of team nursing was established in preference to the key nurse system. Team nursing allowed senior and junior staff nurses to work together with larger groups of patients. New members of staff could better slot into this system and the senior staff nurses recognised that they had a role to play not only in acting as mentors to the student nurses but also in helping the more junior qualified staff to develop. The regrading of nurses had made everyone more conscious of the differences in ability between junior and senior staff. However, interstaff rivalry and conflict remained a problem on the ward and some nurses became disillusioned because, as they tried to develop new ideas, other staff would not be so enthusiastic but as they depended upon their co-operation, once more a sense of frustration set in.

During this time the charge nurse talked to me about how she saw her role as having moved away from patient care and acknowledged an anger that she was being forced to be so concerned with management, research and teaching. She said that she felt largely unsupported by management and lacked contact with her peers in the hospital. She found she rarely managed to get away from the ward because it was so busy and found herself feeling exhausted and constantly looking forward to her weekends off. She felt the nature of ward work had changed with technicalities such as computerisation, which had made simple tasks such as ordering more complicated. She resented not having more of a voice in future changes and being so much under management control. She disliked the attitudes of her co-workers and felt nurses were being brought up to be too critical, tending to show a lack of respect for experienced workers. She felt nurses were too concerned with the technical aspects of care and neglected the basics. She resented having to take her co-workers' views and opinions of nursing care into

consideration knowing that they would soon be moving on and then she would have to change again to suit the needs of another transient group of people. She felt the school of nursing expected her to do too much for the students and because she could not achieve this felt frustrated and constantly criticised. This made her feel under enormous pressure at work and generally unfulfilled in her work as a nurse.

Although the charge nurse did not confide in me her plans, it was not surprising in view of these expressed feelings that not long afterwards, she announced her resignation from hospital work in preference to a new job in the community. On reflection, I think for the project brought to the surface feelings and resentments that had developed over a long period of time and had previously been "swept under the carpet". As the charge nurse worked her notice people commented on how she had changed and how much happier in herself she appeared to be. Before she left she told me that she wished she had made the decision five years before and had not realised it would be so easy to get another job and in particular a promotion. However, I could not help feeling partially responsible for her decision to leave the ward and have wrestled ever since with feelings of guilt and discomfort. For me this event raised several ethical issues about conducting action research and these thoughts are explored further in Chapter 10.

TRANSITION PERIOD: APRIL-JUNE 1989

Once the charge nurse had announced her resignation the project entered an uncertain phase. There was a need for me either to withdraw from the hospital or renegotiate roles with the newly appointed charge nurse. The nursing management reaffirmed their interest in the project by saying that they intended to advertise the post with the project continuing. They also decided to create a post within the hospital entitled Assistant Director of Nursing Services (Special Projects) and suggested that the project would continue to be monitored by this person after I had left. They acknowledged that the project had not been given sufficient support and attention by management and made a commitment to getting more involved. The charge nurse post did not get as far as being advertised because an ideally suited internal applicant came forward. From the research perspective, the new charge nurse had known me in my previous work and had come forward and applied for the job because she felt she had got into a rut and wanted to have the opportunity to reflect on her practice and work collaboratively in a multidisciplinary setting. From the ward's perspective she was a highly experienced charge nurse, having worked on the surgical equivalent to the medical ward for which she was applying. Some of the staff knew her from when they had been learners on her ward and others knew her because she had worked on the ward next door. It seemed that everyone welcomed her appointment and the original charge nurse said she

was happy to be passing on her ward to a known colleague. The only drawback with the appointment was that she was unable to start on the ward until after she had completed her examinations for a part-time degree in Psychology.

However, it was arranged that in the interim an acting charge nurse would be appointed to the ward. During this time it was rather difficult to continue to try and change practice. Participants were reluctant to initiate new ideas without consulting the new charge nurse and there was a sense in which the project was being "held over" until she started on the ward. Frequently during this time meetings were cancelled, and I decided to use the time to review what had taken place and its effect on the ward. With this in mind, I started to interview the multidisciplinary staff to ascertain their perspective on what had or had not been achieved and the reasons why. These interviews were referred to as the "exit interviews" and had already occurred during the project as members of the multidisciplinary team had left the ward to go to other jobs. During this period of time I also gathered similar data to that which had been gathered at the beginning to ascertain if there had been any change. This included a quality assurance measure (Wandelt and Ager, 1976) and observations of ward reports, ward rounds and multidisciplinary team meetings. Thus whilst I remained in frequent contact with the ward gathering data, the focus was not particularly on changing practice but on monitoring whether change had taken place.

During this time I was invited to apply for the post of Assistant Director of Nursing Services (Special Projects) and saw it as a way of being allowed to develop the research ideas in the wider context of the hospital. Discussions centred around establishing the ward as a research and practice development unit and having a formal link with a University, thereby assuring proper academic support for the research. Unfortunately the nursing management decided not to accept this proposal and for a while I felt a sense of disappointment and disillusionment at not being appointed, having been so actively encouraged to do so. The nursing management explained their decision on the basis of not feeling able to work with someone who was really only interested in developing research based practice in the hospital. Whilst the Assistant Director of Nursing Services (Special Projects) was to have the responsibility of developing research based practice throughout the hospital, she was also going to be expected to take on more administrative duties to support the Director of Nursing Services in her post. On reflection, I take pleasure in having been asked to apply for the post and feel it was a vote of confidence in the work that had gone on in the ward. However, I feel disappointed that the nursing management did not feel able to give more commitment to the advancement of practice based research. I feel it is important in a self-reflective account to mention

this event as its effect on me at the time was bound to influence the nature of my relationship with the participants. These issues are explored further in Chapter 10.

In June the new charge nurse and I met on several occasions to renegotiate the project ideas and discuss our future working relationship. The new charge nurse was in many ways different to the original charge nurse. She was research minded and welcomed open and honest discussion about ways in which patient care might be improved. Whilst she identified herself as having got into a rut with her work and therefore felt the need to change wards and start afresh, she did not appear threatened by the changes that were being demanded of her as a charge nurse. She had an interest in professional development, demonstrated by her having spent the last few years completing a part-time degree at her own personal cost. She was not interested in maintaining the status quo but wanted to work together with the multidisciplinary team to improve practice and experiment with new ideas. She saw her role as charge nurse to be advisory, educative and supportive rather than "policing the ward". She had an enthusiasm and energy for nursing and conveyed this in her open style of communication.

In our discussions about the project we explored what had gone on in the past and identified ways in which she would like to develop the research in the future. There was a sense in which I was starting to withdraw from the ward and passing the research over to her and needing to negotiate an entirely different role in facilitating the project. It was agreed that I would leave the ward in August, once the main study data collection had been completed, and then keep contact with the ward through meetings with the new charge nurse on a once-weekly basis as needed. Whilst I was delighted to be in a position to see the research continuing to develop (having invested so much time and energy into it), it does raise issues over the difficulty of withdrawal from an action research study. Although I worked on the ward for a period of one year trying to change practice, my contact with the ward and field notes actually spanned two years from the time of negotiation (April 1988 till June 1990).

POSTSCRIPT DATA: AUGUST 1989 -JUNE 1990

The new charge nurse took up her post on the ward in August and although for some of that month I was still in the clinical area finishing the data collection for the main study, my real contact with her was through regular support meetings which often took place in her own time away from the ward. These meetings continued until June and were used very much as an opportunity for her to reflect on the developments on the ward. During this time she described her struggles to change practice, which interestingly mirrored many of the struggles of the past. The staff had clearly identified

the original charge nurse as getting in the way of change. The new charge nurse identified that the qualified nurses found it hard to adjust to their new roles and responsibilities due to a lack of confidence and lack of skills in communication, supervision, teaching and organisation. There was a suggestion that either the nurses' education had inadequately prepared them for their roles as key nurses or that they had become fixed in task oriented practice through working on the ward over time. Either way she said they found it hard to develop an educative and supportive role in their relationships with patients and colleagues and found prioritising care for individuals problematic. The new charge nurse found it difficult to sustain the momentum of change with an ever changing work force and lack of time. There were times when the ward was so busy that there was really no time for professional development work and she found herself, much against her better judgement, "policing the ward" to ensure standards were maintained. She discussed the total lack of support for innovation within the hospital. She saw the support services as being insufficient and complained bitterly about the inadequate staffing levels and inappropriate skill mix on the ward. She discussed her feelings of isolation and lack of support from management and at one stage described the hospital as being in a state of crisis management. The effect of trying to change practice in this environment was physically exhausting and she found herself becoming disillusioned and despondent about what could be achieved. It is interesting to note that all these issues were identified by the original charge nurse.

Nonetheless the new charge nurse felt that some improvements were made on the ward. The atmosphere on the ward was reportedly different. She felt this was probably due to her giving so much of her own time to support her staff with their problems both off and on the ward. She felt she had managed to create a talking culture where people felt better able to share their concerns and express their opinions and were thus better able to reflect on practice. She had identified with each of the qualified nurses their individual strengths and weaknesses and on these she was endeavouring to work with them. She reported that the structure of the patient's day had been changed so that they were no longer woken up so early and care was being given in a more individualised way through the decentralisation of nursing work. For instance, care planning rounds now took place at the bedside and drugs were given by the key nurses to their own patients. She felt the multidisciplinary team was working together better with the various health professionals relating more directly to the key nurses about specific patients' needs and problems. Although the problems still remained with the management of the house officers, she felt they were more involved with patient drug education, largely because she was reminding them to do it. She also reported that the senior medical colleagues appeared more receptive to change and had been prepared to discuss the possibility of using

aromatherapy and patient self-medication on the ward. Finally the ward was receiving good evaluations from the learners passing through and staff were making special requests to work there.

Perhaps the new charge nurse's greatest strength was that she was articulate and confident and was not frightened of dealing with difficult issues. She felt able to discuss issues of medical domination with her senior medical colleagues and managed to argue the need for beds to be closed on the basis of inadequate staffing.

For me one of the most significant contributions she made was to the research itself. This enabled me to feel comfortable in withdrawing from the ward and passing ownership of the project to her. First, when it became apparent that the new Assistant Director of Nursing Services (Special Projects) was not going to be able to assist in monitoring the project because she was due to go off on maternity leave, the new charge nurse obtained some money from the regional health authority in order that she could carry on with the project. By employing agency staff on the ward to cover her absence, she was able to interview staff about the changes on the ward and write an internal report for the hospital. Second, she became very concerned that the research had still not addressed the lay perceptions of participation in care and in June obtained a junior research studentship from the Department of Health to register for her own PhD in order to carry out this work. While it is disappointing that she was not able to continue leading the developments on the ward it is encouraging to know that this action research study has directly led to further work which hopefully will positively influence future health care practice.

SUMMARY

This chapter describes chronologically what happened in the course of this action research study from the origins of the proposal until the time when one of the participants took over ownership of the project and registered for her own PhD to explore further a particular aspect of lay participation in care. The story of events is told to set the research in context and allow the reader to gain better insight into what happened. By its very nature action research needs to respond to and accommodate the unexpected as it arises in the reality of practice. Without telling the story, the findings can loose their meaning.

The following chapter examines what is meant by lay participation in care. Given that the health professionals in the study demonstrated a limited understanding of lay participation in care, it is useful to explore its meaning in the literature.

CHAPTER 2

LAY PARTICIPATION IN CARE - EXAMINING THE CONCEPT

INTRODUCTION

This chapter explores what is meant by lay participation in care. It begins by describing lay participation in care as an umbrella term used for many different concepts within the literature. Next it explores the various levels on which lay participation is practised and then goes on to explore the nature and development of the concept in relation to two conflicting historical legacies. Thus the emergence of lay participation in care as a key concept within a changing health service is explored in relation to discordant philosophical and political ideologies. It is argued that lay participation in care means different things to different people and it is suggested that this plurality of meanings has led to confusion not only in the literature but also in health care policy and practice. Finally the definition of lay participation in care, as used in the study, is explored.

LAY PARTICIPATION IN CARE AS DEFINED IN THE LITERATURE

Within health care practice lay participation in care is fundamentally concerned with the involvement of non-professionals in the delivery of care in health related institutions (e.g. hospitals) and/or the wider community. It is a loose term that is widely used in the literature to describe various approaches to health care. As a result the literature on lay participation in care encompasses many different and wide ranging phenomena from a range of disciplines (medical sociology, health psychology, social policy, health promotion, nursing and medicine). The body of knowledge on this subject is therefore somewhat fragmentary and inconclusive. Research in the name of lay participation in care covers a wide variety of activities, approaches and facets which include: locus of control (Rotter et al., 1972); self-efficacy (Bandura, 1986); learned helplessness (Seligman, 1975); reactance (Brehm, 1966); information giving (McIntosh, 1974); patient education (Wilson-Barnett and Oborne, 1983); self monitoring (Nelson, 1977); self medication (Webb et al., 1990); compliance (Craig, 1985); goal setting (Janz et al., 1984); informed consent (Burrows-Hudson, 1985); decision making (Kaufman, 1983); consumer satisfaction (Jones et al., 1987); self care (Chang, 1980); informal care (Parker, 1985); customer approach (Eisenthal et al., 1979; Eisenthal et al., 1983; Eisenthal and Lazare, 1976); co-operative care (Grieco et al., 1990); self empowerment

(Roberts and Krouse, 1990); activated patient (Schulman, 1979); community participation (Madan, 1987).

Lay participation in care is currently part of a popular rhetoric. However, on closer scrutiny, some activities labelled as lay participation in care, reveal little evidence of meaningful partnership between health professionals and the lay public. The limitations of some of its meanings and understandings in the literature are discussed in this chapter. The following section explores the way in which lay participation in care occurs at a variety of different levels.

The different levels of lay participation in care

Lay participation in care can occur on many different levels and can be divided into involvement of the individual, family and friends and public in general. However, within these groups, further differentiation can be made to do with both the extent and nature of involvement.

Level 1 - the individual

Lay participation in care can be regarded as the involvement of individuals in their own health, often referred to as self-care in the literature. Levin defines self-care as:

> *" ..... a process whereby a lay person functions on his/her own behalf in health promotion and prevention and in disease detection and treatment at the level of the primary health resource in the health care system"*
> (Levin, 1976)

From this definition it can be seen that lay participation in care is concerned with involving all people within a well-being - illness spectrum (Dines and Cribb, 1993). In self-care there is as much focus on involving the well and healthy individual in health maintenance and disease prevention as there is concern with involving the unhealthy individual in disease detection and treatment (self diagnosis, self medication, self treatment). The extent of possible self-care is clearly going to be determined by an individuals' level of dependence or independence in relation to their position on a health-illness spectrum, plus their knowledge, attitude and skills. Thus the health professional concerned with self-care is likely to be working with individuals in a variety of settings and ways, either as clients or as patients.

Level 2 - involvement of family and friends

Another facet of lay participation in care is the involvement of family and friends in an individual's care. The term friend refers to non blood-related others who are

significant in the patient's life. Again the level of involvement will be determined largely by the extent of dependence or independence of the related individual and the actual nature of involvement will be determined by the individual's state of well-being. Once again family and friends can be involved in health care in a variety of settings; for example within the community as informal carers (Parker, 1985) and in health related institutions as participants working alongside health professionals.

Lay participation in care is as much concerned with the activity of health related decision making as with the development of practical skills in order to promote health, prevent disease, detect and treat illness or adjust to long term illness and death. Decision making can be seen at the individual level in terms of making decisions about patient or client care or at the wider community or society level of making decisions about local and national policy issues that influence health.

Level 3 - public participation

In the literature making decisions at the level of community or society is often referred to as public participation. Maxwell and Weaver (1984) offer five perspectives on what is meant by public participation which can be seen in ascending order of public demands: *consumer protection; public consultation; openness of managerial decision-making; full management participation by public representatives; and heightened individual responsibility and power*.

According to Maxwell and Weaver (1984) *consumer protection*, represents the lower or minimum end of the spectrum of public demand. It refers to the degree of protection against exploitation expected by any user of a service. It includes professional standards, licensing of medicines and practitioners and providers, ethical committees governing research and the notion of informed consent.

Public consultation is concerned with taking into account the feelings and opinions of lay people about the service under offer. This does not necessarily imply lay dissatisfaction when views are not acted upon. In some instances it is enough for the provider to be seen to be listening through regular consumer surveys and for mechanisms to be provided for suggestions and more formal complaints. On the other hand there are some issues lay people feel more strongly about and would wish their views to radically change services. The establishment of voluntary organisations to actively campaign for changes in policy and practice exemplifies this. This form of participation is frequently described as consumerism but needs to acknowledge both the views of consumers of health care (patients, clients, self-help groups) and the views of citizens in general as a contingent user (Klein, 1984).

Openness in managerial decision-making, is also seen as part of public participation. Maxwell and Weaver (1984) suggest that since the health service deals with such sensitive issues and is such a large user of public money, the lay public have a right to know how decisions are arrived at. The establishment of user groups within health care practices allows opportunity for sharing more the process of decision-making.

Full management participation by public representatives allows communities to share in the processes of health policy making and service provision. This ensures that unpopular decisions can be defended. For instance, the Community Health Councils have been established to represent the interests of the lay public in the health service.

Finally *heightened individual and community responsibility and power are* seen as the last form of public participation which engages the most public accountability and participation of all the five public perspectives (Maxwell and Weaver, 1984). This particular perspective is based on the notion that health has become over medicalised (Illich, 1976; Kennedy, 1981) and that the balance must be redressed through empowerment of individuals and communities taking more responsibility for their own welfare.

HISTORICAL LEGACIES

Whilst lay participation in care can be seen to function at different levels, the nature of lay participation in care very much depends upon its underlying philosophical and political underpinnings. Van den Heuval (1980) suggests that there are two conflicting historical legacies that have profoundly influenced the conceptual understandings of lay participation in care; one emerging from a humanistic perspective emphasising self-determination and the other described as the bureaucratic approach to consumerism based on controlling costs, outcome and efficiency. These two distinct historical legacies have led to a plurality of perspectives and confusion of meanings in the literature on account of their different and often conflicting political perspectives. The following section explores these two historical legacies in more detail.

The humanistic perspective

This perspective is derived from humanism which stresses the importance of people and their capabilities. It is thought to have emerged as a challenge to the medical dogmatism in the mid 20th century.

According to Steele lay participation in care in the form of the active patient concept has waxed and waned for the past two centuries (Steele et al., 1987). Prior to the

18th century most individuals had a responsibility for their own health care, usually as a result of necessity (only the wealthy or educated made use of professional services). Within the community people helped each other and some individuals were recognised as having special skills but there was little participation by the majority of people in the development of health care policy. However, the last half of the 19th century saw an increase in medical technology in terms of effective disease prevention (immunisation, antisepsis, and asepsis) and curative measures (serum therapy antibiotics). Together these fostered a gradual increase in medical authority and "the retreat of private judgement" (Starr, 1982). Medicine became established and respectfully recognised as a scientific discipline as doctors and other scientists developed a taxonomy and applied scientific methods to understanding treatment and prevention of disease. Thus during the first half of the 20th century doctors enjoyed unparalleled dominance; their medical authority was seldom questioned and patient acquiescence was assumed (Steele et al., 1987). Engels (1977) suggests that medicine as an institution became a formidable power of social, political and economic invested interests and as a result demands for a return to lay participation in care have been slow to take hold.

The challenge to medical dogmatism arose in the mid 20th century as a result of several influences. First, there is the influence of existentialist philosophy with its emphasis on self-determination and its encouragement of mistrust of authority and doubts about technology (Thomasma, 1983). Second, there is the impact of health statistics revealing the chronic and preventable nature of most illness (Jacobson et al., 1991). Third, there is the effect of advances in medical technology resulting in patients being discharged from hospital earlier or being nursed at home in the community (King's Fund Centre Health and Social Care Communication Unit, 1989). Fourth, there is the development of consumerism within society, arising from a better educated public with more access to health related information through the mass media and leading to public demands to be kept informed and more involved in the care (Jones et al., 1987). These influences challenge the medical domination of health care and have given rise to an interest in health education and health promotion. This interest requires health professionals to rethink their roles in relation to lay people and to develop "educative and supportive" roles rather than continuing to act in the traditional role of expert "doer". By focusing on the three levels of illness prevention, that is, primary, secondary, tertiary prevention, (Caplan, 1964) and on positive health promotion (Downie et al., 1990), it is envisaged that the quality of life for all members of society might be improved. This challenge to medicine as an occupational elite (Harrison et al., 1990) is further supported by the recognition that the vast majority of care in the community is being given by informal carers (Parker, 1985) and also by the public realisation that lay organisations (voluntary and self help groups) as well as alternative and complementary practitioners

make useful contributions to health care practice. This together with the growth of consumerism and the establishment of the feminist and self-help movements has done much to challenge the traditional notions of doctor-patient relationship particularly in areas of patient access to information about their health care and determinants of the quality of care.

It is interesting to note that in spite of these general changes, it is only in recent years that lay participation in care has been a focus of academic attention. Kickbusch (1989) suggests that in the past researchers tended to concentrate on matters related to the organised professional health care system including topics such as the organisation of illness and its treatment which focused on the corresponding patient-professional interactions. In this way the authority of the physician was rarely questioned by researchers and patient behaviour was summed up in the issue of "compliance". It was not until the late seventies that a growing body of work within medical sociology started to radically criticise the medical system and apply a political economic focus (Navarro, 1976). These ideas were made more public by feminists and self-help social movements, interested in human rights.

The humanistic or democratic perspective embraces the notions of empowerment, civil rights and equality of opportunity and is citizen-led (Beresford and Croft, 1993). Beresford and Croft argue that empowerment is a critical concept for practice and they identify four important dimensions: empowering people to challenge oppression and discrimination and take greater charge of their lives; offering people control over the personal dealings with agencies; enabling people to take power by helping them gain confidence, self-esteem, assertiveness, expectations, knowledge and skills; and offering opportunities, structures and resources which are open to people's involvement. However, they also recognise the importance of putting empowerment in context as some environments are disempowering (Beresford and Croft, 1993). They thus identify wider issues for organisations and services to facilitate lay participation in care through empowerment, that is: agreeing not imposing participation, using an amalgamation of top-down and bottom-up approaches, developing skills in individual and political change, bringing together service providers and users, changing outcomes as well as attitudes, equipping people to set their own standards for quality control and evaluation, having a flexible approach to increasing people's say, recognise and tackle different tensions and chains of accountability in different service providers, creating a positive climate for experimentation and risk, and finally disseminating good practice (Beresford and Croft, 1993).

From the above it can be seen that the emergence of lay participation in care is a result of a humanistic perspective emphasising self-determination. However, another and conflicting historical legacy has similarly given rise to this concept based on controlling costs, outcome and efficiency. Van Heuval describes this as the bureaucratic approach to consumerism (Van den Heuval, 1980). This alternative perspective to the development of lay participation in care is explored in the following section through an examination of the changing health service. Finally it is argued that these two perspectives have profoundly influenced the conceptual interpretation of lay participation in care and have led to a confusion of meanings in health care literature, policy and practice.

The bureaucratic perspective

This section argues that the growth of managerialism which has occurred in response to financial and organisational threats to the health service has led to the development of a different understanding of lay participation in care to that of the humanistic perspective. The humanistic perspective, based on empowerment with its emphasis on participation, partnership and power-sharing, is in direct conflict with the bureaucratic perspective based on consumerism, with its own emphasis on economy, efficiency and cost-effectiveness.

Health care provision has evolved over time in response to changing demands. The National Health Service, established in 1948, was seen as a great step towards the goal of an equitable distribution of health services by making services free of charge at the point of use (Baly, 1973). However, since its beginnings two major issues have threatened the realisation of this goal: finance and the organisation of services (Leathard, 1990) . One of the outcomes of these threats has been for lay participation in care to have been given more emphasis in health policy documents. However, this emphasis reveals a lack of understanding of the concept of lay participation in care which is seen as a thread of humanistic health promotion. It is argued that lay participation in care will not alleviate the threats identified unless account is taken of the more fundamental issues at stake.

The first issue in the historical legacy of the bureaucratic perspective concerns finance. From its beginnings the National Health Service has tended to generate costs and place increased demands on public expenditure. The ideology behind its creation was that there should be no financial constraint on patients receiving treatment according to need (Klein, 1983). It was assumed that there was a fixed quantity of illness in society and that the National Health Service would reduce this in time (Beveridge Report, 1942). However, advances in medical technology and improvements in public health have led to increases in the elderly population and chronically sick within society and this, together

with increases in consumer expectations, has placed a never ending burden on the limited resources available for health care. Over the decades more money has been poured into the health services but this public expenditure has never met the changing demands for health care.

Various initiatives have been set up to review finances and plan priorities (Department of Health and Social Security, 1976; Department of Health and Social Security, 1977; Merrison Report, 1979). The main thrust of these plans is to suggest more efficient use of resources and place greater emphasis on community care and preventive services. As a result of economic stringency, lay participation in care, under the guise of consumerism, has become increasingly important within policy documents (Department of Health and Social Security, 1986a; Department of Health and Social Security, 1986b; Department of Health, 1988; Department of Health, 1989; Department of Health, 1990; Department of Health, 1992).

The second issue that threatened the National Health Service was the organisation of services. In turn this has led towards the adoption of the notion of lay participation in care. According to Leathard (1990) four on-going issues surrounded the effective organisation of hospital provision up until the late seventies: resource priorities (already discussed), controversy over pay beds, staff shortages and above all the reorganisation of the whole structure of the Health Service. Reorganisation of the NHS structure in 1974 was needed due to an inherited problem of fragmented and uncoordinated services. Unfortunately it attempted to reconcile conflicting policies (managerialism and professionalism) and this in turn led to further crisis and chaos (Leathard, 1990).

During the late seventies and early eighties the depressed economy imposed cuts and efficiency savings on the National Health Service. During this time the government sought alternative methods of health care provision including the private sector, voluntary sector and informal caring by the family (Department of Health and Social Security, 1981a). Whilst the government was keen to endorse the contribution made by lay people to health care, it ignored the emerging research evidence indicating that informal care had its own costs to bear on those individuals who became carers (Department of Health and Social Security, 1981b). Clearly this endorsement of lay participation in care was driven and solely led by financial interest.

In seeking to prepare health professionals for a role in preventing ill health in the community, the government supported the idea for nurses, midwives, health visitors and health educators to develop their role as health promoters (Department of Health and Social Security, 1976; Department of Health and Social Security, 1977a; Department of

Health and Social Security, 1981a). However, their emphasis was very much on health promotion at the individual level, such as changing lifestyles, rather than addressing more fundamental issues within society connected with the inequalities of health. Thus the government supported the development of the health professionals' role in promotion for cost effective reasons by focusing on a "victim-blaming approach". This indicates a fundamental misunderstanding of what can be achieved through health promotion. Health promotion is not necessarily cost effective and it certainly requires a financial commitment to developing practitioners in that role (Beauchamp and Childress, 1983). Furthermore there is a big debate as to whether promoting health at the individual level is actually effective. In a survey which took place during 1984 and 1985 looking at health and lifestyle and including 9003 men and women of 18 years and over, it was found that circumstances have greater weight than behaviour. That is not to suggest that health education with individuals is of no benefit, but rather that avoidance of behavioural risk factors seems to be protective only to a small degree where involuntary lifestyles are considered unhealthy (Blaxter, 1990).

The government's emphasis on individual responsibility for health is clearly at odds with more modern day understandings of health promotion which emphasise the need for greater commitment to public health initiatives. Furthermore it is argued that the government's focus on whole population health screening rather than targeted family care may well lead to a waste of scarce resources (Stott, 1990). Those educated in current understandings of health promotion are unlikely to perceive their role as being to persuade individuals to change their lifestyle against all odds or to persuade family and friends to take on the role of informal carer to the detriment of their own health, for cost effective reasons. Rather they would want to empower their clients to become involved in care (if that is their wish) or to empower them to challenge government policy and take community action to make healthier choices easier choices where possible. To quote the conclusion of a symposium on health and lifestyle in 1990 which reviewed research that had been supported by the Health Promotion Trust:

> *"It is simplistic to expect health education to advance merely because the research has been done and the facts are known. The difference between health education and health promotion should not be forgotten and neighbourhood and community developments are important. Policy makers, health service budget holders, executives and trainers should all take part in the debate. The importance of shared dialogue rather than advice-giving cannot be over emphasised."*
> (The Health Promotion Research Trust, 1990, p.112)

The nineteen eighties saw a period of rapid upheaval and unparalleled change in the health services. It began with a search for better management which did nothing to re-address the issues being raised by a conflict in understanding of the meaning of health promotion. The introduction of general management in the National Health Service, based on the Griffiths model (Griffiths Report, 1983), had allowed little time for public or professional consultation on its recommendations. The underlying notions of partnership within health promotion were once again ignored. If lay people were to be involved in care, it is argued that they should have been given more opportunity to influence how the service was to develop. The paradox here is that the new management proposals espoused a consumerist spirit but the structures were to actively inhibit meaningful lay involvement (ACHCEW, 1988).

Throughout the eighties a new wave of managerialism brought in new concepts and ideas concerned with resource priorities, targets and reviews. The new managerial approach has two themes: decentralisation and markets used to match provision to consumer demand. The chief criticisms of the new approach concern the emphasis on cost-efficiency, the limitations imposed on choice, the channelling of innovation towards increased economy, the practice of selectivity and the problems of constructing collective outcomes through aggregation of individual choices (Taylor-Gooby and Dale, 1981). For example, the Citizen's Charter (Cabinet Office, 1991) promotes a range of methods for improving basic standards, the availability of choice, the quality of provision and value for money in the public sector, including competition, contracting out, privatisation, performance-related pay. The Charter also emphasises public monitoring of services. However, Taylor-Gooby and Dale (1981) argue that the measures chosen to monitor services are highly controversial and there is considerable concern that the desire to meet the standards skews resource allocation and stifles innovation within services. Whilst such approaches emphasise lay participation in care through choice, critics argue that choice is constrained by knowledge and availability of alternatives, which in turn may be controlled by overall budget and policy objectives. In this sense choice is meaningless and merely serves as rhetoric.

By the late nineteen eighties the government was advocating increasingly the role of lay people in health care but the limitations in what was available immediately became apparent. The 1989 White Paper *Working for Patients* had a central theme of consumer issues (standards, quality assurance, communications, choice); however it really did little to enhance consumer power. Whilst lip service was being paid towards reorienting the health services towards health promotion in line with the WHO statements of "Health for All by the year 2000" (World Health Organisation, 1986), little was being done to encourage public participation in health. As Maxwell and Weaver wrote:

> *"Central government policy in relation to health has recently concentrated on the pursuit of greater marginal efficiency within the National Health Service and the encouragement of private sector alternatives. To plead for more effective public participation is not necessarily in conflict with either of those two approaches, but it is less fashionable than it might have been a decade ago ..... no combination of services is going to be satisfactory for long which does not explicitly recognise and promote the importance of participation by the individual, the local community and national organisations in matters of health."*
> (Maxwell and Weaver, 1984, p.118/9)

Lay participation in care became popularised within management through consumerism but the extent to which true partnership was being offered is doubtful. The term itself was fraught with ambiguity. Stacey (1976) suggests that the concept of patient as consumer undervalues the patient status and is a sociological misconception since in reality patients are both consumers and producers of health by virtue of their participation in the health care process. Van den Heuval (1980) suggests that the meaning of the concept is in need of clarification and that research on consumer satisfaction and evaluation are limited since there is presently no real means of involving consumers in health policy. Whilst Locker and Dunt see such studies as being an indirect form of consumer participation, Van den Heuval (1980) argues that consumer participation should also allow for consumers to assess health needs as well as comment about the organisation and availability of services.

Recent reports on the health service all advocate the notion of the patient as consumer (Department of Health Nursing Division, 1989; Department of Health, 1992). Freedom and consumer control are key features of the Conservative's social policy on the basis that state-dominated services deny people the opportunity to engage in real choices (Clode et al., 1987). However a tension exists between equality and liberty, in that individual choice and individual purchasing power are likely to mean that those with greater levels of resources can purchase a better quality of service. Clode et al. (1987) identify three levels of consumerism and argue that whilst in "fiscal-led" consumerism the distinction between equality and liberty is clear, in "organisation-led" consumerism the distinction is less obvious and in "individual-led" consumerism the right to freedom needs to be balanced more keenly with the right to treatment.

Recent writers on health policy have suggested that the government is using the new managerial approaches (efficiency savings, cost-improvement programmes, performance indicators, general management, and internal markets) to delay or avoid a

crisis in the welfare state (Harrison et al., 1990). They suggest that health policy can be best explained by a combination of neo-elite and neo-Marxist theories. Neo-elite theories are concerned with occupational elites and may explain why the medical profession has come to dominate health care practice. Neo-Marxist theories relate elites to the class structure of the capitalist state. They argue that the demand for welfare state expenditure rises over time (due to demographic changes and expectations) but that capitalists resist increasing taxation to accommodate this by placing instead an emphasis on cost-efficiency. Harrison, Hunter and Pollitt (1990) argue that this is for short term gain only and foresee either a gradual dismantling of the welfare state or for capitalists to support the growth of the National Health Service. Thus lay participation in care can be seen as a political ploy by government to "paper over the cracks" of a disintegrating welfare state.

There are also clear examples of the ways in which recent government policy actively inhibits true partnership in care between professionals and lay people. For instance, the impact of social changes in the early nineteen seventies saw the establishment of the Community Health Councils, which provided a formal and statutory mechanism for the consumer voice in the National Health Service. In the name of consumerism lay members were similarly appointed to Health Authority Committees and Family Practitioner Committees. Furthermore national organisations were established to represent the patients' perspective (The Patients Association in 1963) and to further public knowledge about health care (The College of Health in 1983). Demands for lay participation in care can also be seen through the growth of self-help groups and patient participation groups which were established as a form of local expression of lay interest in health issues. However, it is interesting to note that the major changes in the NHS contained in the National Health Service and Community Care Act (1990) and in the introduction of the Citizens' and Patients' Charters (1991), were seen to strengthen the voice of the patient within the NHS, but have also led to the marginalisation of the Community Health Councils (Association of Community Health Councils, 1992).

Thus the bureaucratic consumerism perspective is very different to the humanistic perspective of lay participation in care and is clearly informed by very different political traditions and understandings of the importance of welfare.

Williams (1989) identifies seven different perspectives on welfare. These are anti-collectivism, social reformism (non-socialist welfare collectivism, Fabian socialism, radical social administration), political economy of welfare, feminist critique and anti-racist critique. In considering first the perspective of the anti-collectivists, they believe that state welfare limits individual freedom, initiative and choice, and leads to excessive demands on state funds. They also argue that provision should come from the private and

voluntary sector as well as through family and self-help. Their political tradition is Right-wing, free market based, encourages economic liberalism, and embraces the New Right position. The next three perspectives of welfare identified by Williams (1989) come under the umbrella of social reformism. Social reformism supports collectivism, that is, state provided welfare and includes non-socialist welfare collectivism, Fabian socialism and radical social administration. The non-socialist welfare collectivists believe that welfare provision is necessary for national efficiency and alleviation of worst deprivation, but also come from private and voluntary sectors (welfare pluralism). The associated political tradition is political liberalism and social democracy. Fabian socialists believe that the welfare state is central to the transformation of society through redistribution of wealth and the creation of more equal, just, harmonious society to counter the inequalities of the private market. The associated political tradition includes social democracy and Fabian socialism, whereas the radical social administration stream is new and includes the empiricism of Fabianism and the structuralism of Marxism. The fifth perspective, political economy of welfare, believes that the welfare state is an outcome of fundamental conflict between capitalism and working class and has its political tradition in Marxism. In contrast, the Feminist critique believes state welfare provision to be important for the amelioration of women's lives but also recognises that it reinforces female dependency and the sexual division of labour. Like the political economy of welfare, this perspective draws on the political traditions of Marxism but includes as well liberalism, socialism and radical feminism. The final perspective on welfare identified by Williams (1989), the anti-racist critique, believes that state policy reflects shifting relations between imperialism, capitalism and patriarchy. It regards the welfare state to be a form of institutionalised racism within society and supports this claim with reference to denial of access, second class provision, reproduction of racial divisions and maintenance of immigration controls. The anti-racist critique includes Black radicalism, socialism, Marxism and Black feminism.

It could be argued that whilst the bureaucratic consumer perspective is clearly derived from anti-collectivism and Conservative policies, the humanistic perspective of lay participation in care is derived from a coalescence of the six remaining perspectives, that is, the three strands of social reformism, the political economy of welfare, as well as the feminist and anti-racist critiques.

From the above it can be argued that not only is lay participation in care practised on different levels but also its nature and development are derived from two historical legacies of conflicting political intent. Thus lay participation in care is seen to mean different things to different people, depending on their individual principles and values. One has to question whether government policies which advocate lay participation in

care, actually offer freedom of choice to the individual. Resources are scarce and the cynic might suggest that the government is more concerned with off-loading its responsibilities onto the consumer than being concerned with freedom of choice and improving the quality of health services. In this way lay participation in care might represent a mere tokenism. By paying lip service to lay participation in care the government might wish to make its policies more acceptable to the public. True participation in care would require a radical change in the health service to become more than social rhetoric (Brearley, 1990). It would require a model of partnership based on equality and offering choice through empowerment. It would require a different type of professional capable of sharing knowledge with lay people rather than limiting access to specialist knowledge only to experts. It would also require freedom of choice as to whether one participated in care or not. As Cook (1987) points out "unbridled consumerism is not even always what the consumers want".

Having identified, in the literature, a plurality of perspectives, the final section of this chapter gives a personal account of what is meant by lay participation in care in respect of the study.

LAY PARTICIPATION IN CARE AS DEFINED IN THE STUDY

The focus of the present study is on the involvement of patients and their close family and friends in patient care in a hospital ward setting. For the purpose of the study McEwen's definition of lay participation in care is used (see page 21).

This definition is chosen as it clearly places lay participation in care within the context of health promotion. It emphasises the need for lay people to be involved in all levels of health care and whilst acknowledging the importance of the individual in health care shows an appreciation of the need for lay involvement in wider community and societal health initiatives. Research into lay participation in care has focused generally on the individual (Kendall, 1991). For example, informed choice (Burrows-Hudson, 1985), patient education (Wilson-Barnett and Oborne, 1983), and compliance (Eraker et al., 1984). However, the present study is concerned with health professionals changing their approach to work from a traditional role of "doer" to a more facilitative role of "enabler" and thus a broader focused definition is needed. Whilst much of the health professional's work is concerned with the individual, it seems wise to have a definition that allows for the possibility of a variety of initiatives developing, including those with a community or societal focus.

McEwen's definition does not solely concentrate on the patient and acknowledges the invaluable contribution made by informal carers (Parker, 1985) such as close family and friends. The focus of the study was to enable patients and their close family and friends in hospital to be more involved with care with a view to better preparation for discharge. The study is therefore concerned not only with self-care but also with the involvement of other lay people, if this is seen to be important by the patient. Finally the usefulness of McEwen's definition is further clarified by his identification of some key underlying concepts which seem highly appropriate to a study of the changing role of health professionals in fostering lay involvement in care (McEwen et al., 1983).

McEwen identifies the main underlying concepts involved in lay participation as "self-help", "demedicalisation or deprofessionalisation" and "democratisation". Self-help is seen as the active involvement by an individual in all aspects of his or her own health care rather than the traditional passive role normally associated with being a patient. Demedicalisation or deprofessionalisation is seen as the process whereby tasks normally thought to fall within the medical or professional sphere are taken on by the individual. Democratisation is seen as a desire on the part of the lay person to assume responsibility for decision-making with regard to the wider aspects of social policy and health care provision. These concepts clearly place McEwen's definition within a humanistic perspective rather than the bureaucratic consumer perspective.

Chapter 1 gives a personal account of my own interest in humanism and health education and health promotion. It is therefore not surprising that the values underpinning these concepts form the basis of my own understanding of lay participation in care. However, in the same way that it is difficult to universally define lay participation in care, it is similarly difficult to define health promotion in a way other than as a set of values or principles (Dines and Cribb, 1993). It is important therefore to explore the relationship between lay participation in care and health promotion.

The emphasis on lay participation in care as part of health promotion can be seen in the numerous World Health Organisation health definitions over time. However, whilst lay participation in care is emphasised, the underlying philosophical and political underpinnings have not always been made clear. For instance, in the nineteen fifties, partnership was seen to be a key issue in health education as illustrated in the following quote: "Health education is grounded both philosophically and theoretically in the model of client-professional partnership" (World Health Organisation, 1954). However, this statement does not identify explicitly the philosophies and theories to which the World Health Organisation is referring. Later in the nineteen seventies the World Health Organisation suggested that people have "the right and duty to participate individually

and collectively in the planning and implementation of their health care" (World Health Organisation, 1978). This statement reflects confused thinking in that to "have a right" suggests an element of choice, whereas "the duty to participate" suggests the opposite. It also places considerable emphasis on the individual to maintain health. Later in the nineteen eighties, the World Health organisation produced a discussion document on the concept and principles of health promotion which called for integrated action at different levels to deal with factors influencing health, including economic, environmental, social and personal factors (World Health Organisation, 1984). The political commitment to health promotion was specified and it was recognised that health promotion programmes may be inappropriately directed at individuals at the expense of tackling economic and social problems (World Health Organisation, 1984). Since the nineteen eighties lay involvement in care has focused on "effective and concrete public participation" (World Health Organisation, 1984) and at "enabling people to increase control over, and to improve their health" (World Health Organisation, 1986).

Thus health education and health promotion are concerned with maximising an individual's potential to achieve the best possible health through individual, community and societal initiatives. Within health education and health promotion lay involvement in health care has become increasingly important. Internationally it is recognised as one of four conceptual reorientations in approach which differentiate traditional health education from current health promotion strategies. According to the European Region of the World Health Organisation these four reorientations include:

"- *From health prescription to health promotion.*
- *From individualistic behaviour modification to a systematic public health approach.*
- *From medical orientation to recognition of lay competence.*
- *From authoritarian health education to supportive health education."*

(Kickbusch, 1981, p.3)

Lay participation in care can thus be seen as a part of a movement within health promotion away from paternalist approaches to participatory models. Beattie (1991) develops this idea by setting out the different strategies that are available in contemporary health promotion in terms of two bipolar dimensions (authoritative-negotiated and individual-collective). He draws interesting links between these two dimensions and the shifting professional boundaries in health promotion as well as the conflicting political philosophies that underpin such approaches. Beattie (1991) suggests that within the different strategies for health promotion is embedded a distinctive paradigm for the professional-client relationship which is commonly bound-up in political ideology. He

sees "health persuasion techniques" as being part of a "deficit" model expressed through "prescriber" professional-client relationships and being linked to traditionalist "conservative" political ideology. Beattie also argues that "legislative action for health" is based on a "deprivation" model, which offers "custodian" professional-client relationships and has arisen from broadly "old-left" groupings being "reformist" in nature. He identifies the "personal counselling for health" strategy as being linked to an "opportunity" model with health professionals acting as "counsellors" and allying this to the "libertarian" politics associated with the "new right". Finally he suggests that the "community development for health" strategy is based on an "emancipation" model which stresses the role of professional as "advocate" and is broadly linked to "new left" ideology which is "radical pluralist" in nature.

From Beattie's (1991) work it can be seen that lay participation in care shifts the professional boundaries in health promotion from expert directed, paternalist, prescriptive to more client-centred, participatory, and participative approaches. From his argument, it can also be seen that lay participation in care is inherently political and appears to mean different things to different people, depending on their political persuasion.

It is noteworthy that whilst nursing has been quick to respond to social changes and introduce major educational reform emphasising the nurse's role in health promotion and lay participation in care (United Kingdom Central Council for Nursing, 1986), the profession has failed to be explicit about its interpretation of the term. Partnership in care is heralded as a new approach to nursing by nurse academics (Kitson, 1987; Salvage, 1988) and nursing policy makers alike (Royal College of Nursing, 1985; United Kingdom Central Council for Nursing, 1986; Department of Health Nursing Division, 1989) but it is unlikely to be translated into practice until its underlying principles and values are determined and are seen to be compatible with current health care practice.

SUMMARY

It can be argued that lay participation in care functions at different levels (individual, family and friends, public) and has been developed in the context of two conflicting historical legacies drawing on different philosophical and political traditions. The plurality of meanings have been explored and the confusion in understanding within the health care literature, policy and practice discussed. Finally the definition of lay participation in care as applied in the study is explained in terms of it being clearly located within a humanistic perspective and as part of an underlying theme of health promotion. The following chapter reviews some of the research undertaken on lay participation in care and explores the way in which different conceptual interpretations limit the sophistication of research.

CHAPTER 3

EVALUATING THE RESEARCH ON LAY PARTICIPATION IN CARE

INTRODUCTION

As discussed in Chapter 2 lay participation in care means different things to different people. It can be practised at different levels (individual, family and friends and public participation) and has a variety of approaches depending on the philosophical and political persuasion of those involved. Given that an action research approach is taken in the study, and thus the direction of change is dependent on the participants' views of lay participation in care, this chapter focuses selectively on research relevant to the participants' understanding of the concept and in particular at the level of the individual (patient) and at the level of family and friends. Therefore research relevant to hospital care provides the main review, although one small section explores the research done on informal care in the community. This is done to highlight the need for professionals in hospital to be more aware of the needs of family and friends.

The chapter begins by reviewing both the professional and lay perceptions and attitudes towards lay participation in care. Next the link between lay participation in care in hospital and informal care in the community is made. Following this, the research evaluating lay participation in hospital care is explored. The diverse and fragmentary nature of this type of research is acknowledged and, as a means of presenting it more coherently, it is divided into those studies which examine an isolated component of lay participation in care and those studies which have taken a more comprehensive approach. The studies which have taken a more comprehensive approach are further subdivided into those which focus on one-off encounters between health professionals and patients or clients and those which focus on lay participation in care as an overall philosophy in hospital settings.

In general the studies examined have tended to draw on positivist and interpretive epistemologies. The limited value of many of these studies is discussed and the need for more practice based, action oriented, collaborative studies explored. Predominantly studies have tended to demonstrate a lack of understanding of the complex nature of lay participation in care and this is explored through the critical examination of individual studies.

LAY PARTICIPATION IN CARE: PERCEPTIONS AND ATTITUDES

Perceptions and attitudes towards lay participation in care in hospital have been examined from both the professional and lay perspectives. This section begins by reviewing those studies which address the professional perspective and is followed by those studies which review the lay perspective.

Studies addressing health professionals' perceptions of lay participation in care

Studies of professional perceptions of the concept have tended to draw on positivist and interpretive epistemologies and have included the use of structured attitude scales, interviews and field work. The limitations of using attitude scales to examine complex phenomena and of looking at perceptions as mere theoretical constructs through interviews is discussed. The need to examine this concept in detail and in the reality of practice is advocated.

Various attitude scales have been used to ascertain health professionals' views on the concept of lay participation in care (Pankratz and Pankratz, 1974; Citron, 1978; Linn and Lewis, 1979; Brooking, 1986). These scales focus on different aspects of the same phenomenon including patient self-care (Linn and Lewis, 1979), patients' rights and nursing autonomy (Pankratz and Pankratz, 1974), patients' rights in decision making (Citron, 1978) patient and family participation in nursing (Brooking, 1986), and are therefore difficult to compare.

One has to question whether attitude scales are the most appropriate means of understanding health professionals' perceptions of lay participation in care. Brooking (1986), having designed such a scale, argues the need for a more qualitative study to look at such a complex phenomenon in more depth. For instance, she suggests that a qualitative approach might be best used to ascertain why nurses' seniority or age should be such an important determinant of attitudes towards patient and family participation, whether exerting control helps nurses to cope with stress, how patients and relatives feel about their enforced passivity and what strategies patients and relatives use to negotiate a more active role and/or information. Given that lay participation in care means different things to different people (Maxwell and Weaver, 1984) the attempt to quantify and generalise seems inappropriate. Furthermore one might also question the validity of such a tool. Brooking's questionnaire focuses very much on looking at participation in relation to the nursing process. It is therefore concerned with participation in care at the individual level and ignores wider concepts related to the community or societal level of participation. One part of Brooking's questionnaire consists of a list of nursing tasks

which require comment on whether the care should be performed by a patient, relative or nurse. It therefore focuses very much on involvement in practical skills and does not allow for individual circumstances to be taken into account. For instance, it does not look at the wider ethical issues of whether informal carers want to get involved in care or whether some prefer to see the patient's hospitalisation as a form of rest and respite from the burden of caring for a dependant. The tone of Brooking's questionnaire is also very authoritarian and controlling and does not really explore more sophisticated issues such as professionals' views on the empowerment of patients. For instance, a typical item on the "Relative Planning Subscale" is worded:

> *"In planning a course of rehabilitation after a stroke, the nearest relatives should be invited to contribute their ideas"*

Whilst clearly this statement allows a respondent to agree strongly or disagree strongly on a Likert scale, it does not address the more sensitive issue of whether health professionals feel they should control the situation to the point that relatives need to be "invited", thus indicating a flavour of professional dominance. Another sensitive issue not explored by such a scale is whether the relatives' input should be seen as a mere "contribution" given that they may indeed be an informal carer in the future rehabilitation programme. In this way attitude scales of this type can be viewed as being somewhat superficial, possibly meaningless and therefore probably invalid.

Another major problem with the research that looks at health professionals' attitudes is that it tends to concentrate on theoretical views. In general this research relies on self report questionnaires and does not explore attitudes and behaviour in the reality of practice. Views given in this type of research might be at the worst false statements due to use of fashionable rhetoric or at the best theoretical guesses rendered meaningless when applied to practice. For instance, respondents might claim to involve patients in care and express positive attitudes towards the concept, however in the reality of practice they might feel threatened by sharing their expert knowledge and as a result might actively inhibit participation in practice.

Thus there are problems in taking a positivist approach to research and in using structured instruments to measure complex phenomena such as attitudes. There is clearly a need for research that looks at professionals' perceptions of lay participation in care in more depth, possibly through interviews and certainly through participant observation examining the concept in practice. However, studies in the literature which have attempted to examine participation in care from a more qualitative perspective have

tended to continue to explore theoretical views and do not address the professionals' perceptions in the reality of practice. Again this type of research is open to question.

However, a study that clearly attempts to look at professional perceptions of lay participation in care in more depth is reported by Weiss (1986). In the study a stratified sample of 72 nurses, physicians and members of the general public met together in small tripartite dialogue groups each month for 20 months, in order to mutually identify health care behaviours that effectively involve patients in their own care. A content analysis was done on 200 hours of verbatim transcripts from the dialogue sessions and yielded 1245 patient involvement behaviours. These were then systematically reduced to four key norms that existed regarding involvement of patients in their own care: overt contracts in health relationships; egalitarian communication between patient and professional; patient access to broad-based information; and tailoring of treatment programmes, self-care and lifestyle modification. It could be argued that these interviews elicit a more sophisticated understanding of professionals' perceptions of lay participation in care but the findings should be viewed with caution due to the sample selection relying on interested volunteers and the size of the sample not allowing for results to be generalised. Further research is needed to address these limitations and also to determine whether the findings would improve patient care and whether the nature of the contemporary health environment would allow such forms of patient involvement.

Another qualitative study using an ethnographic approach to uncover the perceptions of primary nurses toward the notion of patient participation is reported by Jewell (1994). In the study a group discussion was led by the researcher with four primary nurses within a rehabilitation unit for elderly people. Whilst the study is limited by the small sample size it succeeds in reporting a more in-depth understanding by the nurses of lay participation in care. For instance, they recognise that lay participation in care concerns a general approach to care rather than a specific procedure. The nurses identify the need for both formal and informal mechanisms to facilitate lay participation in care. The formal mechanisms include the involvement of patients, through the nursing process, in planning and evaluating care whilst the informal mechanisms refer to the on-going nurse-patient exchange. The participants also recognise that collaboration involves mutual informing or negotiation between patient and nurse. Whilst this qualitative study gives clearer insight into the nurses' perceptions of lay participation, it is still only dealing with their understandings at the theoretical level. Of greater interest would be whether in reality they actually do involve patients either formally or informally in their care. As with many other studies examining this phenomenon, another point to note is the researchers' apparent limited understanding of lay participation in care. Given that lay

participation in care means different things to different people, one might reasonably expect researchers to be more explicit about their own values and principles guiding their understanding of this concept. Instead researchers tend to draw on general definitions and fail to discuss findings in relation to a broader understanding of the philosophical and political issues that underpin the concept.

In a paper reported to be based on clinical observations and research findings, although giving no details of the methodology used to gather these data, Robinson and Thorne (1984) attempt to examine lay participation in care in reality through qualitative analysis. In their work they explore the phenomenon of family "interference" and suggest that these behaviours are located within the context of the family's evolving relationships with health care providers and tend to occur due to a dilemma in trust between the family and health professional. The authors argue that this dilemma of trust occurs because of a discrepancy in expectations. Families who enter the health care system expect to share responsibility, collaborate on decision-making and negotiate care that is mutually satisfying. However, they soon discover that information is withheld or distorted, that their views are not valued and that, overall, they are expected to comply passively with the professional health provider's view of care. Robinson and Thorne go on to describe a pattern of behaviour where frustration and anger result in family complaints, criticisms, non-compliance, and even sabotage of patient care. They argue the need for professionals to not only recognise these patterns of behaviour but to educate families to deal better with the system, which might include teaching such skills as assertiveness and "constructive manipulation". Whilst the study is poorly explicated, the authors demonstrate a broader understanding of lay participation in care which includes notions of empowerment.

From the above it can be seen that research looking at professionals' attitudes towards lay participation in care tends to be positivist in nature and generally uses structured measurement scales to assess their perspective. The validity of using such measures is open to question. Lay participation in care is a complex phenomenon and means different things to different people. Structured instruments are unlikely to include all the relevant aspects for each individual and it is doubtful that respondents share common understandings when responding to the same of issue. In this way structured instruments are unlikely to accurately measure the health professionals' perceptions of the lay participation in care. Whilst other more interpretive studies tend to examine the concept in more detail, they still deal with the topic at a theoretical level and so the application of findings to practice is doubtful. Furthermore studies of this sort tend to use small sample sizes and it is unlikely that the categories that emerge from the qualitative

analysis are fully saturated. Thus the findings frequently are not sufficiently developed to be generalised. Furthermore researchers do not define adequately their own understandings of lay participation in care and as a result findings are often not discussed within an adequate framework. Thus the philosophical and political implications of findings are frequently ignored. It is interesting to note that whilst research indicates that professionals hold positive attitudes towards lay participation in care, there is little evidence that they translate this into practice (Haug and Lavin, 1981; Brooking, 1986). This suggests that either health professionals are less committed to the concept than first assumed or that they are prevented from acting on their beliefs in practice. The need for further research looking at professional perceptions of lay participation in care when confronted with the concept in reality is needed urgently.

The following section reviews those studies that have examined lay attitudes towards lay participation in care. By comparison to professional perceptions, these studies have found lay attitudes to be less positive and also to vary between different social groups.

Studies addressing lay perceptions of lay participation in care

Studies on lay perceptions of involvement in care are riddled with the same problems as studies concerning professional perceptions of care. Most studies attempt to measure attitudes through structured instruments and some studies, purportedly interested in the same concept, focus on different aspects, thus making comparison of the findings difficult. The fragmentary nature of this group of studies make findings difficult to compare and as a whole largely inconclusive. Once more they tend to focus on theoretical perceptions rather than deal with the issues in reality. Bearing such a limitation in mind, there appears to be a suggestion in the literature that lay perceptions vary with age, in that the younger population hold more positive attitudes than the older population. Given that much of the lay care in the community occurs with the elderly, this is a significant finding worthy of further study. In particular it would be useful to focus on the views of the elderly who have been confronted with this concept in reality. Differences in social groups also suggest different views being held towards this concept. This emphasises the need to acknowledge that lay participation in care means different things to different people and cautions against making generalisations among and between groups.

Brooking's (1986) study uses a self completion questionnaire designed to examine current practices, opinions and attitudes towards patient and family participation in nursing care. Findings reveal that whilst all groups studied express positive views

towards the concept of lay participation in care, professionals are the most positive, followed by relatives and then patients. However, it is not really possible to generalise from the study on account of the lack of sensitivity of a structured instrument to measure such a complex phenomenon and also since there appear to be variations in the views of lay people. For instance, some patients and relatives, particularly those described as "uneducated working class" people, indicate negative attitudes towards participation. Clearly findings from this and similar studies which draw on a positivist epistemology need to be critically evaluated.

However, the relationship between age and attitude towards lay participation in care appears to be a recurring feature in the literature. For instance, Haug and Levin (1981) reveal differences in lay people's acceptance of lay participation in care in relation to age. In a survey of 466 members of the public and 86 physicians in a Mid-western state of America questioning physician authority; a younger group of the public appear to exhibit stronger consumerist attitudes.

Again Cassileth et al., (1980) report that whilst most patients in their study accept the ideal of patient participation, there is also a link between young age and more acceptance. The study, which includes 256 cancer patients completing an Information Styles Questionnaire and the Beck Hopelessness Scale, is limited in that there is a potential source of bias arising from the fact that patients studied were under treatment in a major urban medical centre. The setting itself may have encouraged preferences for information and patients who seek treatment in large medical centres may differ from those who go elsewhere for cancer treatment. This again points out the difficulties of using a survey method where it is not possible to explore with participants in more depth the reasons for their responses.

Whilst it is very difficult to compare findings from the various studies undertaken, it appears there is a link between younger age and greater acceptance of involvement in health care. But one needs to question what motivates different groups to give different opinions. For example, some research suggests that rather than holding positive attitudes towards lay participation in care, lay people feel they are being manipulated and coerced into compliance by professionals.

In a small scale study, that does not look at age as a factor and is based on a convenience sample of twelve patients who were interviewed concerning their views on being involved in decisions concerning their own treatment and nursing care, findings suggest that some patients are more concerned about doing what is right, that is, pleasing

the nurse, than participating in decisions concerning care (Waterworth and Luker, 1990). This raises some interesting issues which imply that patients may indeed be reluctant collaborators in care because they feel coerced into doing so by professional staff. This is at absolute odds with the true notion of lay participation in care which would see the decision by a patient not to participate in care as a form of participation itself. The question of coercion would not enter into an understanding of lay participation in care that sees itself as a thread of health promotion in which patients are empowered to make decisions which may be different to the one a health professional may have preferred.

Thus the study demonstrates the complexity of lay participation in care and shows that researchers can be using the same words with entirely different meanings. However, the significance of the study should not be underestimated as it may be an indication that those interviewed similarly did not understand the meaning of the concept and were more influenced by fear of having work off loaded onto them as a result of financial constraints within the health service. Furthermore it is suggested that some health professionals are indeed not using the notion of lay participation much beyond the level of "tokenism" (Brownlea, 1987) and this is seen as a form of "manipulation" rather than true partnership in care (Brearley, 1990). On a methodological note the lack of biographical detail of the participants in Waterworth and Luker's (1990) study is disappointing and, given that a grounded theory approach usually continues until categories are saturated, the small sample size makes acceptance of the findings problematic.

In another small scale study (Biley, 1992) , interviewing eight informants, using a modified grounded theory approach to discover how patients feel about participating in decision-making about nursing care, tentative findings suggest that patients can gain from indulging in self-determined behaviour; can gain from being in control of what might amount to only a small aspect of their care in an environment where they essentially lack control because they are too ill; do not have enough information and are restricted by organisational and situation constraints. Whilst these findings appear to contradict the findings of a considerable number of other studies exploring the information needs of patients, it should be noted that such studies have tended to be more related to medical decision-making, focusing on cure rather than nursing decision-making focusing on care. The study emphasises the difficulty of drawing conclusions from small scale studies and highlights the conflicting nature of findings. It demonstrates that it is hard to make any general sense of what is written on the subject of lay participation in care.

As mentioned previously, there would appear to be some discrepancy as to whether all groups of lay people indeed want to participate in care. Pendleton and House

(1984) suggest that the lay person's desire for participation in care is related to age, socio-economic status (including education) and affliction with chronic illness. This again stresses the importance of health professionals taking an individual approach in assessing patients' desire for involvement in care. However, research would suggest that health professionals underestimate patients' preference for participation (Strull et al., 1984). In a study of 210 hypertensive outpatients and 50 clinicians, questionnaires were used to explore three aspects of decision making. Findings show that clinicians underestimate patients' desire for information and discussion and overestimate patients' desire to make decisions. Previous studies have shown that patients prefer more medical information than they receive (Svarstad, 1976; Boreham, 1978; Faden et al., 1981).

Given that professionals appear to underestimate patients' preference for involvement, it is interesting to look at those studies that have not only looked at attitudes but also attempted to look at the extent to which it occurs in practice. To some degree Brooking (1986) examines this in her study and demonstrates that whilst nurses indicate that a high level of patient and family involvement is acceptable, patients and relatives report little participation in care. This finding is supported by Batehup (1987) but again relies mainly on data gathered by means of questionnaire. Batehup reports that, whilst relatives of stroke patients express moderate positive attitudes towards participation, little actual participation occurs in practice. Carter (1990) also focuses on the involvement of relatives in her study, which aims to identify the needs and concerns of patients' relatives on two medical wards. In the study semi-structured in-depth interviews are used with a convenience sample of 20 relatives and 8 nurses and observations are made of nurses' notes and handover reports. Whilst once more the limitation of the sample size is a concern and whilst the study would have benefited more from some observation of practice, a content analysis reveals that relatives' needs for reassurance, patient contact and involvement are largely not met. Generally contact with staff is unplanned and relatives use patients as their main source of information. There is a tendency for health professionals to be patient centred to the exclusion of the relatives' needs.

It is argued that from the literature it is not clear what health professionals and lay people really feel about lay participation in care. Findings from different studies indicate different things. However, little research has been done in this country and findings from studies in other countries may not be transferable to the British setting and culture. Furthermore there is a variety of interpretations of the meaning of lay participation in care, which means that the further use of structured instruments to examine this concept may not be appropriate. The use of questionnaires and interviews only really addresses respondents' theoretical understandings of the concept. Given the complex nature of this

phenomenon with all its ethical and political underpinnings, there is a need to examine the ideas of participation in reality. What people say they would like to do in theory may indeed be very different to what they actually do in practice due to lack of will, ability or opportunity. The need for more qualitative practice based studies, possibly using action research, has been identified elsewhere in the literature (Brooking, 1986; Batehup, 1987; Brearley, 1990). Given such methodological flaws, it would appear that health professionals articulate positive views towards lay participation in care in theory, but may hold more reservations in practice. Likewise, lay people hold positive views of the concept but it is interesting to note that their views appear not to be as positive as those held by professionals and also that relatives' views appear to be more positive than patients'. The literature indicates that there may be a link between younger age and greater acceptance of lay participation in care. However, there is some evidence to suggest that lay people may feel coerced and manipulated by professionals into accepting lay participation in care. In conclusion it is argued that findings should be viewed with caution given the methodological weaknesses discussed. Again lay perceptions have only really been examined in theory and there is a need for more action oriented, practice based studies to explore the concept in reality.

The following section describes the research into informal care in the community which clearly identifies the need for health professionals to acknowledge more the importance and value of lay care. The need for health professionals to take more opportunity in hospital of involving lay people in care is also discussed. Given that the participants in the present study tended to concentrate on the involvement of patients and in particular family and friends in care, this seems to be an important area to examine.

RESEARCH ON INFORMAL CARE IN THE COMMUNITY: IMPLICATIONS FOR HOSPITAL PRACTICE

Lay participation in care in the community is often referred to in the literature as informal care. In a comprehensive review of the research on informal care, Parker examines the demography of lay care in the community (Parker, 1985). She suggests that in the future there is likely to be an increase in the number of people requiring care in the community because of the relationship between age, gender and disability. Given that the majority of community care at the present time is done by informal (lay) carers and the fact that current policies tend to support the continuation of this practice (HMSO, 1971; HMSO, 1981; Department of Health, 1988; Department of Health, 1992), it is unlikely that lay people will be relieved of the burden of care. Whilst it might be regrettable that the state is unwilling or unable to offer alternative forms of support and care for dependants, this does expose the need for health professionals both in community and

hospital settings to consider new ways in which lay people might be better prepared for these caring roles in the community.

Walker (1982) suggests that the social division of community care is changing and that the family no longer cares for its dependants. However, Parker (1985) explores this myth and suggests that the evidence she reviewed shows unequivocally that families do care for their dependent relatives in the community. Reviews of the literature show that the major burden of informal care in the community falls on women and in the main tends to be left to individuals rather than be shared amongst other family members (Parker, 1985; Goodman, 1986; Nolan and Grant, 1989). As the proportion of married women who are in paid employment has increased there is a question as to whether this may mean a reduction in the future population of potential carers. However, the tendency at present is for women to take on the task of caring in addition to their work, or instead of their work, and not to pass on the responsibility to others. Of particular concern is the fact that because research tends to focus on the cared-for person rather than the carer, at present little is known about the needs of these carers or the extent to which they are involved in care. As a result this group of people tends not to be visible and has been ignored traditionally by policy makers and health professionals alike. The need for health professionals to take a broader view of the patient (and one that includes consideration of the needs of the family and friends) is identified as a neglected form of nursing practice (Nolan and Grant, 1989). But little is known about the health professionals' attitudes towards carers and their ability to facilitate closer contact with families and friends in order to assess and facilitate their needs. Such activity would constitute an aspect of lay participation in care. There is clearly a need for health professionals in hospital to take account of what is happening in the community and recognise the vital role lay carers are playing.

It is also not clear whether family and friends wish to be more involved in care. Whilst research into preferences for care patterns indicates that informal care with professional support is the preferred option for most people and most dependent groups, it is not known whether this system of health care actually meets the carer's own personal needs. From the carer's perspective, the cost of caring brings economic and health concerns. For example, there is now clear evidence that caring can impose a toll on the mental well-being of carers (Parker, 1985). In particular women, when compared with male carers, have been shown to suffer as they are more likely to have to give up their jobs, lose money, experience stress and are less likely to receive services. The need for health professionals to involve family and friends in care in hospital, so that they might support potential carers in understanding the ramifications of taking on this burden of

care, is paramount. As Goodman (1986) suggests, the research on the experiences of the informal carer must raise questions about the present organisation and delivery of nursing care and thus there is a need to look at new ways of including lay people in health care practice. From a review of the literature on informal care, Nolan and Grant (1989). suggest that carers have the following needs: information, skills training, emotional support and some form of regular respite from their role as carer. There is a need for research to be done in hospital settings to explore ways in which the health professionals' role might change their ability to take more account of these issues. As Twigg (1986) points out, professionals need to be sensitive to the needs of lay carers as there is danger of exploitation. By treating carers as co-workers, a co-operative and enabling model of professional support can be offered which neither undermines the carer's ability nor leaves the carer feeling overburdened. The relationship between professionals and informal carers is clearly important given the evidence which suggests that carers are sensitive to the reactions of professionals and that poor reactions increase carer stress levels as well as inhibiting them from seeking further professional assistance (Nolan and Grant, 1989). Health professionals in all settings need to address this issue and it is argued that much could be gained from those working in hospital settings being more aware of the invaluable contribution made by lay people to health care.

Lay participation in care in hospital is a growing phenomenon. The use of the nursing process, primary nursing and certain models of nursing, for example, Orem's model (1985), which place the patient and his or her family at the centre of decision making, care planning and evaluation (and stress the patient's autonomy and independence), has led to more emphasis on self-care and informal care in hospital. However, as previously argued, whether in practice professionals are actively encouraging lay participation in care remains open to debate. The following section reviews the research that has attempted to evaluate lay participation in care in practice.

RESEARCH EVALUATING LAY PARTICIPATION IN CARE IN PRACTICE

As a manifest social phenomenon, the body of knowledge on lay participation in care is ever increasing, but the disparate nature of much of this research means that it is largely inconclusive. This section explores a selection of research from a range of activities which constitute lay participation in care. Studies focusing on isolated components of lay participation in care are reviewed along with other studies focusing on a more comprehensive approach to the concept. In this way the different meanings given to lay participation in care and levels of sophistication in its interpretation and operationalisation are examined.

Research focusing on isolated component approaches to lay participation in care

Lay participation in care is concerned with a general approach to health care and yet much of the related research has focused on isolated component parts of this approach. These studies take a fragmented and reductionist approach to lay participation in care and attempt to measure in isolation the effect of individual variables or component parts of lay participation in care. For instance, some studies examine the effect of isolated variables on the individual in terms of knowledge, attitudes and behaviour. Previous reviews of the literature on patient and family participation in care give a broad, albeit superficial, overview of these types of study (Brooking, 1986; Brearley, 1990). The isolated variables normally considered in relation to lay participation in care are stress (Selye, 1976), locus of control (Rotter et al., 1972), self-efficacy (Bandura, 1986), learned helplessness (Seligman, 1975) and reactance (Brehm, 1966). Whilst these concepts are complex, their contribution to the literature on participation in care lacks sophistication since, by concentrating on the individual alone, no account is taken of the broader social influences that may also have an effect. From a review of this body of literature it can be deduced that participation increases feelings of control for the patient and that this in itself is worthwhile and can lead to improved outcome (Brearley, 1990). However, these feelings of control may be illusory because an individual may be unable to actively exert such control in reality because of overbearing social factors. Therefore it is argued that studies (Auerbach et al., 1976; Laborde and Powers, 1985) showing the importance of assessing individuals' perceptions of locus of control in order to predict whether they would be suited to lay participation in care may be rendered meaningless in practice.

One has to question whether it is really possible to measure these concepts at all and the significance of this. Research to date on these isolated components has tended to follow experimental designs, with the manipulation of key variables. These studies do not take into account the difficulties of manipulating variables, with human beings, in complex organisations. The fallacy of this approach has been discussed elsewhere (Parlett and Hamilton, 1977).

The lack of sophistication in this approach to research can be demonstrated in a study by Langer and Rodin (1976). In an experimental design 91 American nursing home residents were divided into an experimental and control groups. With the experimental group, responsibility for themselves and choice is advocated and a plant is given for them to look after! The control group does not get a plant to look after but is encouraged to see themselves as the staff's responsibility. Questionnaire ratings and

behavioural measures are used and the experimental group appears to be more alert, more active in terms of participation and has a better sense of well being. If this experiment is to be taken seriously, one has to question in what way giving a plant to elderly people really facilitates their participation in care. In many ways it seems a patronising gesture that does not hold with broader understandings of lay participation in care. On the other hand the experimental design is at fault because not all the variables are controlled (not that they ever could be) and it is be hard to differentiate whether participation in this instance is to do with the plant, the emancipatory conversation or the Hawthorne effect, so often referred to in research textbooks looking at the experimental design (Polit and Hungler, 1985).

Given that lay participation in care is a complex phenomenon and is more about an approach to care than any one specific phenomenon, the reductionist methods used are questionable.

Other studies tend to focus on the social roles and relationships in lay participation in care. In particular studies have looked at the doctor patient relationship in terms of challenging medical dominance through calls for demedicalisation (Illich, 1976), and changes in professional control (Freidson, 1961; Freidson, 1970). These studies also contribute to an understanding of the family in relation to illness (Locker, 1982) and an understanding of lay conceptions of health (Calnan, 1987). Furthermore, they question traditionally held beliefs, confronting issues such as the meaning of consumerism (Stacey, 1976) and compliance (Stimson, 1974).

To exemplify this the research that has been done in the area of information giving (McIntosh, 1974) and patient education (Wilson-Barnett and Oborne, 1983) is explored for conceptual changes in understanding. These studies relate directly to other studies looking at informed consent (Burrows-Hudson, 1985), decision making (Kaufman, 1983) and compliance (Craig, 1985) and again show differences in sophistication in understandings of the basic concept of participation. Studies on information giving demonstrate that patients are dissatisfied with the amount they receive; that information which aids understanding can reduce pain and speed recovery; that satisfaction about information received causes patients to comply with advice; and that lack of information actually prevents patients from complying (Tuckett and Williams, 1984). However, such studies tend to concentrate more on the process of relaying the information rather than the actual content of the information. For instance, Davis looks at the way in which the doctor-patient relationship influences compliance (Davis, 1968). The lack of detailed focus in this and similar studies is a limitation in

contributing to an understanding of lay participation in care. Tuckett and Williams (1984) argue that there is a need to investigate clear criteria on what should be told to which patients and in what circumstances. They suggest that the lack of criteria could be interpreted as further evidence that information giving in medical settings principally functions not to inform but to control (Tuckett and Williams, 1984).

Other empirical studies on comprehension of information given for informed consent show that research subjects often do not understand much of that to which they have consented (Silva and Sorrell, 1984). This clearly raises ethical issues about the individual's right to self-determination. Clearly from these findings, studies that do not address whether information given by professionals is understood by lay people, cannot be identified as lay participation in care. As Wilson-Barnett and Oborne (1983) argue, there is a clear distinction between information giving and patient education. They suggest that sensitive assessment and fulfilment of patients' information needs redefines patient teaching. Levin makes yet a further distinction:

> "Patient education *assigns a unique social role to the learner - that of a sick person under the care of another.* Self-care education, *in contrast, does not assume sickness, thereby assigning a generic meaning to care - that is, to look after."*
> (Levin, 1978 p.171)

This distinction refers to the way in which within patient education the focus is on what the professional thinks is good for the patient, whereas in self-care education it is determined by what the learner perceives his needs and goals to be and which may or may not be in conflict with the professionals views of need. This is another level of enquiry which is not really addressed in the literature. When looking at the effect of patient teaching assessment it is made mainly in terms of compliance. Whilst medically oriented compliance studies measure aspects of patient behaviour such as adherence to medication routines (Griffiths, 1990), sociological approaches take a different view of compliance in that they are more concerned with self management or self regulation (Stimson and Webb, 1975; Conrad, 1985).

In a study by Conrad (1985), which uses data from eighty in-depth interviews with people suffering from epilepsy, the patients' perspective is explored as to why they take, or do not take, their medication. These findings show that patients are in fact actually asserting control over their disorder rather than being non compliant as might be argued from the medical perspective.

Osman (1990) argues that there is a need to see patients as "experimenters" rather than as "non compliers". In assessing compliance, he advocates that a self regulating model should be used rather than a compliance model. In other words health professionals should accept the patient's need for control and testing with their treatments, rather than be at odds with it. Bearing in mind these different levels of understanding within the literature, one has to question whether it is possible to review research studies and conclude with statements such as "patient education improves compliance" (Cohen, 1981). Clearly in each study there is a different understanding of the term "patient education" and "compliance" and as such it makes findings difficult to compare and thus restricts wider generalisation. Cameron and Best (1987) conclude from an overview of compliance issues that there is a need for greater theoretical organisation, standardisation of interventions, closer examination of process and setting variables, and a more systematic evaluation of the process and outcome of initiatives.

Thus it can be seen that whilst some studies contribute to a better understanding of phenomena such as compliance through use of interpretive approaches, they still study isolated aspects of lay participation in care and do not always deal with issues in the reality of practice. Again the need for practice based, action oriented studies is highlighted.

The following section examines research which takes a less reductionist approach and focuses more broadly and more realistically on lay participation in care.

Research evaluating comprehensive approaches to lay participation in care

This chapter concludes with an overview of the research that appears to start from a more comprehensive understanding of lay participation in care. A comprehensive understanding is differentiated by the fact that rather than concentrating on an isolated component such as self medication or self monitoring, a more general approach to the definition of lay participation in care is taken, requiring a change in relationship between the health professional and lay person. The section again explores the different levels of sophistication in understanding of the concept of lay participation in care. It is argued that these approaches have a greater potential to embrace lay participation in a fuller sense by offering empowerment to patients (or clients) and their family and friends. However, on closer examination, many of these studies fail to demonstrate a broader understanding and often appear to be locked in cost-effectiveness and medical model frameworks despite the humanistic rhetoric espoused. The chapter begins by reviewing

those studies that examine the empowerment of patients in "one-off" encounters with health professionals, and then looks at those studies that attempt to introduce lay participation in care as an overall philosophy within a hospital setting.

Research on empowering patients in one-off encounters with health professionals

The outcome of empowering patients in health care settings is sometimes described as the "activated patient" (Sehnert and Eisenberg, 1975; Steele et al., 1987). It tends to focus on one-off encounters concerned with patient-physician decision-making but issues can be easily related to any health professional (Roter, 1977; Bernarde and Mayerson, 1978; Brody, 1980; Quill, 1983; Greenfield et al., 1985). Brearley (1990) suggests that often this kind of patient-practitioner interaction is still controlled by the health professional and opens to question what is meant by the "activated patient" concept in each of the research studies. Even models advocating more participation in health care stop short of true empowerment. For instance, the models described by Szasz and Hollender (1956) describe a continuum of patient-physician interaction progressing from the passive patient and active professional ("activity - passivity model"), through more active patient and less active professional ("guidance - co-operation" model), to equality of activity ("mutual participation"). However, as Freidson (1970) notes, the model stops short and there is a need for two other models on the same continuum: one where the patient guides and the physician co-operates and another where the patient is active and the physician is passive. Brearley (1990) advocates one step further where the patient functions alone without professional support. These models tend to ignore the impact of the environment which in itself can be disempowering and inhibit the activated patient concept. For instance, an impoverished environment might not offer a range of care options and thus the patient or client may not be in a position of real choice.

Roter's (1977) study is an example of research empowering patients in one-off encounters with health professionals. In a study where 294 hypertensive patients are randomly allocated to two groups, one group (experimental) is given an educational input that encourages the identification and rehearsal of questions about their condition and treatment before visiting their doctor, and the other group (control) who is given general information about the clinic. In the study, participation is seen to be problematic. Whilst question-asking is increased in the experimental group, the "activated" patients display more tension, anxiety and anger as a result of their encounters. This outcome is seen as patients being more empowered to be assertive with their physicians. However, it could also be viewed as yet another study that looks at this concept from within fairly narrow limits. Preparing patients for isolated encounters is not really supporting fully the

concept of lay participation in care and could be arguably morally indefensible if patients are then abandoned with minimal input and not really followed through to a stage of feeling fully empowered to deal comfortably with health care professionals.

Greenfield et al. (1985) attempt a similar study to Roter's study but here the patients are suffering from peptic ulcers and the nature of the educational input is different. Patients in the experimental group are given individualised information about their conditions and the logic underlying their care is explained. They are encouraged to ask questions and discuss their concerns when they meet the physician and are given opportunity to rehearse this beforehand. Findings show that there is no difference between the control and experimental groups in terms of questions being asked. However, audio tape recordings of the patient-physician interaction show that the experimental group are twice as effective as the control group patients in obtaining information from the doctors. Greenfield et al suggest that the activated patients employ more subtle and non-directive strategies in their efforts to elicit information. The study shows the complexity of trying to measure outcome and establish causal relationships when dealing with human interaction.

To what extent the educational inputs described in such studies can really claim to be effective methods of patient empowerment is debatable because the long term follow up is lacking in these studies. Furthermore to what extent the changes noted are the direct outcome of educational input is again open to question. However, as a means of seeing lay participation in care as changing the power balance between health professional and lay person, they represent a more sophisticated understanding of the concept than those studies that really see outcomes in terms of compliance only.

Other studies have examined the activated patient but in such cases initiation has come from the physician (Eisenthal and Lazare, 1976; Roter, 1977; Eisenthal et al., 1979). In these studies professionals are encouraged to adopt a "negotiated approach to patienthood". This involves them in eliciting from patients their expectations about treatment and negotiating an acceptable course of action. The negotiated approach correlates significantly with patient satisfaction in that patients feel better and get their desired disposition. These studies demonstrate a more sophisticated understanding of lay participation in care due to the way in which they disentangle and clearly specify satisfaction and adherence as outcome measures. The different dimensions of the negotiated approach are correlated with the subjective-perceptual and behavioural outcomes. Satisfaction is most strongly related to patients' perceptions of being heard, understood, and aided in their efforts to articulate requests. Adherence to agreed courses

of action is seen as the product of actually participating in treatment, planning and in having one's original treatment goal met.

Other studies have explored patient empowerment in health care practice through such means as "contingency contracting" (Schulman, 1979; Janz et al., 1984). However, the studies are few and far between and findings cannot be compared due to the different foci taken and different understandings and interpretations made of concepts examined. Steele et al. (1987) suggest that the active patient concept has not been adequately scrutinised and advocates the need for theory driven research programmes. Nonetheless such studies do represent an attempt for health professionals to examine lay participation in care at a more sophisticated level than looking at isolated components of a phenomenon. For instance, in the context of the present argument, the study of self-medication and compliance is meaningless without addressing the patient's view on drug taking and what their intentions would be when measuring adherence. This can only be done by addressing the power balance between health professional and patient and enabling the patient to articulate his or her own view and perspective. The activated patient concept could be about doing this as long as the continuum of participation is understood to be broader than the "mutual participation" model identified by Szasz and Hollender (1956).

The following section reviews those studies where an overall approach to patient care has been organised around the concept of lay participation in care. In particular the focus is on hospital settings.

Research on lay participation in care as an overall philosophy in hospital settings

Within hospital settings one of the most well-established frameworks for introducing lay participation in care with a focus on self-care is that articulated by Orem (Orem, 1971; Orem, 1985). In this model patients are viewed as possessing "self-care agency" which is the ability for engaging in self-care. When self-care agency is not adequate to meet therapeutic self-care demands, self-care deficits occur. The health professional's role is to assist persons with their self-care deficits to maximise self-care and improve health. Orem's model has been used in a variety of research studies with patients (Krugar et al., 1980; Miller, 1982; Harper, 1984; Kubricht, 1984).

Miller's (1982) study involves an evaluation of the self-care agency of 65 ambulatory adult patients with diabetes. Using a grounded theory methodology she identifies ten categories of need, recording the data on a care plan based on Orem's

concepts of self-care deficits and self-care requisites. Similarly Kubricht (1984) uses Orem's model, as well as others, to identify therapeutic self-care demands expressed by thirty adult outpatients undergoing external radiation therapy. In both studies the contribution to the body of knowledge is the identification of self-care needs for specific groups of patients from the perspective of the client. However, it is unclear how the categorisations are made in relation to Orem's model and whether the application of a structured model to a data set expressed inductively is appropriate. It could be argued that by forcing the data to fit Orem's model the researcher is at risk of misinterpreting what the patients or clients are telling them. Whether the sophisticated nuances of the concept are addressed is unclear.

However, in Harper's (1984) study which involves the testing of hypotheses deduced from Orem's Model, there appears to be a lack of understanding because the criteria used to measure differences are open to criticism. She compares 30 black, elderly, hypertensive women who received a self-care treatment programme with a similar group who received a control teaching programme. She assesses both groups for knowledge, health locus of control, self-care medication behaviours, medication error rates and hypertension. After 4 days she found the experimental group compared favourably in all variables except for hypertension. After 4 weeks this positive trend did not occur for any variable except knowledge of medication. However, it is not clear to what extent lay participation was really being carried out. Whilst care might have been designed around a framework of Orem's self-care philosophy, the focus on compliance with self-medication may indicate a lack of sophisticated understanding of the concept.

Thus it can be seen that the use of a comprehensive model, such as Orem's Model of self-care does not necessarily imply a full and proper understanding of the concept. The fact that demonstration projects have shown that self-care can be cost-effective (Zapka and Averill, 1979; Ondrejka, 1983) and that self-care increases satisfaction and compliance (Harper, 1984; Chang et al., 1985) suggests that some self-care initiatives are still within the managerial or medical model framework rather than being concerned with self-care as a form of empowerment. Empowerment is not an easy concept to work with in a system dominated by professionals and bureaucracy. Roberts and Krouse (1990) argue that if self-care is to be regarded as a mechanism for empowering consumers, then nurses must engage in a deliberate process to foster control and greater responsibility within their clients. They suggest that the process should be deliberate because client control is difficult in health care settings dominated by the medical model and health care professionals often lack training in sharing control and power with their clients. Roberts and Krouse advocate that a model of negotiation be used as an interaction strategy which

allows both the client and professional to share power and control. However, they acknowledge that this model is a small factor in the change that needs to occur to develop a humane and person-centred health care system. Use of such a model would raise issues of efficiency, ethical decision-making, and legal and moral dilemmas.

Some studies, using comprehensive approaches to self-care, have taken more account of the whole environment in establishing such a philosophy of care. These studies examine those organisations that have a formal commitment to the concept, not only in the way health professionals involve lay people in care but also in the way the organisation is co-ordinated to deliver such an approach. It is argued, however, that even in these environments a lack of sophisticated understanding of the concept of lay participation in care still remains.

The implementation of a comprehensive approach to lay participation in care can be seen in the establishment of self-care and co-operative care units in North America (Chwalow et al., 1990; Grieco et al., 1990; Shendell-Falik, 1990). These units purport to be implementing a self care philosophy which gives control back to the patient with the health care team working alongside the patient to achieve mutual goals. They have been set up as hospital initiatives and thus do not represent the attempt of individuals to work in isolation outside a supportive environment. However, the extent to which these initiatives represent "bottom up" approaches responding to community needs or "top down" approaches forced by management, remains unclear. Some evidence exists in the self-care unit at the Newark Beth Israel Medical Center (Shendell-Falik, 1990) to suggest that more egalitarian relationships amongst staff have been addressed in order to facilitate the innovation and the use of patient contracts would indicate that lay-professional relationships are client-led. However, in the papers reporting on the co-operative care unit at the New York University Medical Center, an authoritarian stance appears to have been taken with no patients being admitted without a suitable care partner to support them (Chwalow et al., 1990; Grieco et al., 1990). This imposed criterion seems at odds with the principle of participation where patients may not want to be nursed by a member of their family and friends.

Whilst articulating a health promotion focus which addresses self-empowerment of the patient, the initiating factor of this type of innovation appears to have been for cost effective reasons (Chwalow et al., 1990; Grieco et al., 1990; Shendell-Falik, 1990). Whether this comprehensive approach truly embraces the notions of a more liberated understanding of lay participation or not is questionable. However, such case studies do

represent an attempt to examine the concept of lay participation in care more comprehensively than those studies which focus on isolated components of the concept.

Whilst Shendell-Falik (1990) gives useful details of the process of establishing such units, no evidence of rigorous evaluation is given. Claims to success for the self-care unit rest on achieving a consistent earlier discharge, compared with the usual hospital discharge rate. However, it is rather disappointing that such a case study of innovation does not systematically ascertain the perceptions of those involved in the change (lay and professional) on the process and outcome issues. Findings should therefore be viewed with caution as it could be argued that those writing the accounts have a vested interest in claiming success. As regards early discharge, findings vary with those of the co-operative care unit (Chwalow et al., 1990; Grieco et al., 1990). In a study that gathered data between 1983 and 1989 a shorter length of stay is reported compared with the traditional hospital unit (Grieco et al., 1990) whereas the length of stay for the same co-operative care unit between 1981 and 1983 is reported to be longer. This finding is thought to be due to patients on admission to the co-operative care unit being more sick than the control group. The focus on early discharge reinforces the impression that such initiatives are driven by financial need and whether the overall philosophy is as humanistic as claimed could be open to question. Another factor for consideration is whether these special units attract a certain type of person, both as patients and as staff, and therefore comparing early discharge rates with those of the more traditional centres remains doubtful.

Whilst claims to success rest heavily on cost effectiveness, process analyses on the co-operative care unit, between 1981 and 1983, indicate that patients assigned to co-operative care become more knowledgeable about their care, as do their care partners. Co-operative care patients are also significantly more informed about their health problems, their treatment, and are better able to demonstrate their ability to adhere to treatment before being discharged. Co-operative care partners are also found to be more involved in health care activities of the patients after discharge than their control partners. After discharge there is evidence of a positive effect on patient understanding and self-management (Chwalow et al., 1990). It is not entirely clear how these data were gathered but the use of statistical analysis suggests it was through the use of questionnaires. Whether claims to success can be made on the basis of this method of evaluation is questionable. Structured questionnaires can only ask specific questions and do not encourage a more sophisticated response. Once again the concentration on "being informed" and "compliance" may not address underlying complex issues of the patients' preference for information and self regulation which have been discussed elsewhere in

this review of the literature. Once again, whilst a comprehensive approach to this concept is taken, the attempt to measure its success by breaking it down into isolated components for evaluation without allowing for more open ended process responses to be taken into account paradoxically shows a lack of sophistication in understanding.

SUMMARY

This chapter has examined the health professional and lay perceptions and attitudes towards lay participation in care. It is argued that much of the research drawn on is questionable because studies draw on positivist epistemology and attempt to measure the complex phenomenon of lay participation in care in a simplistic manner, using structured instruments of questionable validity. Other studies which have taken an interpretive approach tend to be few and, as with more quantitative studies, tend not address the issue of lay participation in care in the reality of practice. Frequently, isolated components of lay participation in care have been studied and even when a more comprehensive approach is taken, the researchers demonstrate a limited understanding of the concept by not referring to the underlying philosophical and political dimensions. The tendency has been for researchers to ignore public participation and focus primarily on the involvement of patients or clients an their family and friends in the physical aspects of care or in the decision-making process. Another issue for researchers has been "information-giving" which has been frequently linked to "compliance", again demonstrating a narrow view of lay participation in care in which empowerment is not really addressed. The need for future research to address lay participation in care in its full complexity and in the reality of practice is stressed. By taking an action research approach, the present study attempts to address, in a more meaningful way, the issues of lay participation in care in a hospital setting.

CHAPTER 4

ACTION RESEARCH: EVALUATING CHANGE IN PRACTICE

INTRODUCTION

In the present study an action research approach is used to describe and evaluate the process and impact of introducing lay participation in care within the context of a ward environment. This chapter explores the meaning of action research through a historical review of the conceptual changes in understanding both within education and nursing. Action research is described in the context of new paradigm research. Its legitimacy as a science in contributing to social knowledge is discussed. Drawing on the arguments of Schon (1983), concerning the crisis in professional knowledge, the need for action research studies within the practice discipline of nursing is explored. Finally, hospital based action research studies in health care, and nursing in particular, are critically examined in view of the changes in conceptual interpretation of action research. In conclusion a cautious note is drawn about the differences between education and nursing and the need to be selective in adopting approaches to action research taken from another discipline.

DEFINITION AND HISTORICAL DEVELOPMENT

Action research is not easily defined as it is an approach to research rather than a specific method. Throughout the literature the term is used loosely and widely. However, the following definition is quoted frequently and reflects the more recent changes of emphasis in the understanding of action research which have emerged in the last decade:

> *"Action research is simply a form of self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own practices, their understanding of those practices, and the situations in which the practices are carried out."*
> (Carr and Kemmis, 1986 p162)

An understanding of these more recent conceptual changes in action research and appreciation of the wide differences in studies being labelled as such can be gained by examining the historical development of the approach.

Origins of action research

It is often claimed that the term "action research" was first used in 1946 by a social scientist named Kurt Lewin. However, Corey (1953) suggests that Collier, Commissioner for Indian Affairs 1933-1945, was another independent proponent of action research. Lewin was particularly concerned with inter group relations and minority problems in the USA during the nineteen forties and felt that the research needed for social practice should be a form of social management or social engineering. In a seminal paper, Lewin places much emphasis on the need for practical studies with the social scientist co-operating with practitioners in making change through a problem solving approach. Lewin identifies a framework for action research which includes a spiral of steps, each consisting of circles of planning, action, and evaluation (Lewin, 1946). This framework can be seen as the basis for many of the more modern definitions of action research (Clark, 1972; Ebbutt, 1985; Carr and Kemmis, 1986; Elliott, 1991). Lewin also highlights three important conceptual themes which are retained in more recent definitions: its *participatory* character, its *democratic* impulse, and its *simultaneous contribution to social science and social change* (Carr and Kemmis, 1986).

However, whilst some or all of these components are incorporated into studies labelled as "action research", there are many differences between the various approaches. These various approaches can be identified by their different philosophical underpinnings. This chapter explores these changes in philosophical underpinnings of action research over time and in particular draws on the development of action research in education. Action research continues to be used in many different disciplines (Rapoport, 1970; Kingsley, 1985), but the development of action research in education is of particular interest to nurses owing to the parallels that can be drawn with nursing research (Meyer, 1993).

Parallel developments in educational and nursing research

Currently there is a resurgence of interest in action research in education (Kemmis, 1993). Similarly action research appears to be gaining momentum in nursing (Greenwood, 1994). Kemmis (1993) identifies seven reasons for this renewed interest in education. These reasons include a professional demand for practitioners to develop research roles to investigate their own practice, a growing perception of the irrelevance of contemporary educational research, an increasing interest in practical reasoning (as opposed to technical or instrumental reasoning), a rise in "new wave" methods emphasising participants' perspectives, an increase in the accountability movement requiring practitioners to justify their practices, a revived interest in developing professional practice as a result of public criticism and finally, an increased awareness of

action research itself. It is interesting to trace the development of research in education, not only because nursing appears to follow a similar pattern but also because these developments influence people's understanding of action research itself. Nurses interested in action research tend to draw from the literature in education and whilst this is appropriate, given the similarity of these two practice based disciplines, there also needs to be a recognition of the differences which warrant caution in applying theories from one discipline to another.

Action research can be seen as a rejection of more traditional positivist and interpretive views of science in dealing with theory development within a practice discipline. In education, early research tended to be quantitative in nature and experimental in design. This is not surprising given that in the same way nursing borrowed positivist techniques from medicine in its neophyte years of research, education borrowed similar techniques from its related discipline of behavioural psychology (Lacey and Lawton, 1981). Later both disciplines rejected these approaches as being too mechanistic and inappropriate for dealing with humans in complex organisations and turned in favour to more sociological interpretive approaches which took account of individuals and their subjective meanings (Parlett and Hamilton, 1972). However, with time there is a growing dissatisfaction in both disciplines in that these descriptive accounts neither address the realities of changing practice nor acknowledge the potential contribution of practitioners in developing knowledge (Carr and Kemmis, 1986). This disenchantment with traditional approaches to research has occurred in other disciplines too and has led to the emergence of a new paradigm of research (Reason and Rowan, 1981). The following section examines the rejection of positivist and interpretive notions of science and explores the way in which action research, as part of the new paradigm, may be a more appropriate way to develop knowledge in a practice discipline.

Rejection of positivist approaches to research

A positivist approach to scientific enquiry has dominated the field of research for the past century. A new paradigm for the philosophy and practice of research has been increasingly called for by those involved in "human" sciences. Reason and Rowan (1981) put forward a new paradigm of research which is collaborative and experiential, stressing the need for researchers to work **with** and **for** people rather than **on** people. Action research clearly falls within this new paradigm of conceptual thought.

Susman and Evered (1978) highlight the deficiencies of positivist science and by contrast examine the scientific merits of action research. They make five points: no methodology is value neutral; self-directed behaviour means humans cannot be treated as

objects; it is not possible to ignore the role of history in the generation of knowledge; a system is more than the denotative language that exists to describe it; and the fact that one cannot exclude the knowledge of the inquirer in understanding the generation of knowledge.

The choice of methodology (traditional versus new paradigm) very much influences the process and outcome of research findings. If science is a product of the human mind, it is imperative that the method is chosen which best suits the subject under study. Those involved in social science might strongly make the case that positivist science is inappropriate when dealing with human inquiry. Furthermore, research focused on change is dealing with the unpredictable and therefore it is imperative that attention is paid to the process, as well as the outcome, of an innovation. Action research draws from a different understanding of science which allows for the process of change to be explored rather than solely attempting to measure outcome. Clearly, in all research it is important that the knowledge of the inquirer and their philosophical understandings of the nature of science are understood. Action research makes this explicit, hence the importance of making these philosophical distinctions explicit in this thesis.

Susman and Evered (1978) suggest that action research can correct the deficiencies of positivist science by being future oriented, collaborative, implying system development, generating theory grounded in action and being agnostic and situational. In these ways it responds to the practical concerns of social life. On the question of action research being scientific, Susman and Evered beg the question of what is meant by "science". They suggest that if being scientific implies a positivist concept only, then clearly action research is **not** scientific. However, they go on to assert that action research does contribute to the growth of knowledge, albeit a different type of knowledge and would therefore advocate that other philosophical viewpoints can be used to legitimate action research such as praxis, hermeneutics, existentialism, pragmatism and pragmaticism, process philosophies and phenomenology.

Thus action research has developed as part of a new paradigm of conceptual thinking. Whilst it clearly draws little from the positivist view of science, which aims solely at *prediction*, it does bear some relationship to the interpretive view of science, which is more concerned with *explanation*. However, the following section argues that action research goes beyond the limitations of the interpretive approach in the development of a different type of knowledge more appropriate for practice disciplines.

Rejection of interpretive approaches to research

Carr and Kemmis (1986) describe the interpretive approach as having originated from social phenomenology (Schutz, 1967) as well as an understanding of the sociology of knowledge (Berger and Luckman, 1967). Central to the interpretive view is the idea that social reality depends upon the individuals' interpretation of it and their interaction with each other to establish social norms. Referring to a "New Sociology", Carr and Kemmis write:

> *"Society is not an 'independent system' maintained through the relationship of factors external to its members. Rather, the crucial character of social reality is that it possesses an intrinsic meaning structure that is constituted and sustained through the routine and interpretive activities of its individual members. The 'objective' character of society, then, is not some independent reality to which individuals are somehow subject. Rather, society comes to possess a degree of objectivity because social actors, in the process of interpreting their social world, externalise and objectify it. Society is only 'real' and 'objective' in so far as its members define it as such and orient themselves towards the reality so defined."*
> (Carr and Kemmis, 1986, p.85)

Interpretive social science is a generic term used to describe different qualitative approaches to the development of social knowledge. Central to such approaches is a commitment to describe social action in relation to the meaning attached to it by the social actors.

Over the decades nursing research has tended to turn to more qualitative methods. Duffy (1985) compares the appropriateness of quantitative and qualitative methodologies for nursing research with reference to epistemological origins, sampling, validity and reliability. She advocates the use of more qualitative methods to generate nursing theory. Swanson and Chenitz (1982) suggest that qualitative research in nursing is needed because quantitative methods are unable to apprehend the nature of the world of patients and tend to produce research that falls short of meaning for the world of practice and fails to provide direction for the improvement of patient care.

Field and Morse (1985) give an overview of the application of qualitative approaches to nursing and refer to the many qualitative nursing research studies that have used interpretive approaches such as ethnography, grounded theory, ethnology, ethology, ethnoscience, ethnomethodology, analytic sociology and phenomenology. However, new paradigm researchers argue that whilst qualitative approaches are of some value, they fail

to deal with the theory practice gap. Kent (1990) criticises Draper (1990) for assuming that it is a lack of qualitative methodology in nursing research that has led to the failure of nursing theory explaining nursing action in a way that can be understood. Kent argues that:

> *"Draper's analysis of the theory practice mismatch identifies the problem as related to research methods but he does not seem to recognise that it is the philosophical assumptions underpinning the scientific approach to nursing research, that gives rise to this problem."*
> (Kent et al., 1990)

Within education, Carr and Kemmis (1986) criticise the interpretive view of science and suggest that action research, as part of the new paradigm of research, goes beyond the limitations of the interpretive view. Their main argument concerns the failure of the interpretive model to question the origins, causes and results of actors adopting certain interpretations of their actions and social life thus neglecting the crucial problems of social conflict and social change. Action research compensates for this by being concerned with practice as a whole, that is, taking into account the social, historical and political dimensions.

Carr and Kemmis (1986) also argue that it is not enough to construct social reality from a plurality of subjective meanings. They suggest that one needs to look also at how individuals' interpretations and actions are influenced by external factors and circumstances. Carr and Kemmis (1986) further argue that the interpretive view does not take account of situations when people's self understanding is illusive or deceptive and as such fails to deal with the reality of practice. They suggest that it is not sufficient to take only the actor's interpretations into account since these may be rationalisations that obscure the true nature of the situation. Furthermore the actors may simply not be aware of the unintentional outcomes of their practice. Theoretical accounts might be then construed which attempt to explain phenomena falsely. In order for theoretical accounts to be useful to practice, the accounts need to address the unintentional as well as the intentional. By taking a holistic and eclectic approach, action research is able to look at both these dimensions. In action research the process of constant feedback to participants allows for meanings to be checked for accuracy and opportunity for further explanation to be given.

Finally another major criticism of the interpretive tradition concerns the distance between the researcher and the research itself, in terms of changing practice. In common

with positivist approaches, the researcher aims to describe social reality in a neutral disinterested way. The interpretive account is written and by uncovering meanings and significance, those who choose to read it may be more informed and enlightened but still may not feel the commitment to change. Thus the interpretive approach does not offer an adequate account of how theory relates to practice. Carr and Kemmis write:

> *"It is precisely because an individual's identity is so closely related to their values, beliefs and attitudes inherent in the style of thought of the social group to which he or she belongs that any alternative interpretation of what he or she is doing will invariably be resisted. Far from changing individual's conceptions of themselves or others, any new interpretations will be perceived as an emotional threat to the individual's self-concept and discarded as 'unrealistic', 'ridiculous' or 'irrelevant'. Because it fails to deal with the question of why the possibility of change should be opposed in this way, the kind of practical effects that the interpretive theories claim to produce will not occur."*
> (Carr and Kemmis, 1986, p.97/98)

Thus action research, along with other participatory forms of research, has moved into a new paradigm of thinking which rejects the more traditional approaches of positivism and interpretivist. Reason (1988) summarises several new paradigm studies and presents the theoretical and methodological debates in collaborative human research. Whilst little nursing research has been done which reflects this perspective, it could be argued that it is the most appropriate way forward in developing a body of knowledge relevant to nursing practice. Drawing on the arguments of Schon (1983) concerning the crisis in professional knowledge, the following section explores the need for action research studies within the practice discipline of nursing.

CRISIS IN PROFESSIONAL KNOWLEDGE: IMPORTANCE OF ACTION RESEARCH TO PRACTICE DISCIPLINES

Schon (1983) describes a crisis of confidence in professional knowledge. He suggests that whilst professionals claim to contribute to social well-being, they have put their clients' needs ahead of their own, and hold themselves accountable to standards of competence and morality. Critics have equally claimed that the professions are serving themselves at the expense of their clients. Schon suggested the root of the problem lay in the inadequacies of professional practice, in dealing with the complexity of practice. He writes:

"Let us consider, then, how the crisis of confidence in the professions has been interpreted by professionals who have given serious thought in their own fields to the adequacy of professional knowledge. On the whole, their assessment is that professional knowledge is mismatched to the changing character of the situations of practice - the complexity, uncertainty, instability, uniqueness, and value conflicts which are increasingly perceived as central to the world of professional practice."
(Schon, 1983, p.14)

Schon suggests that the awareness of uncertainty, complexity, instability, uniqueness and value conflict had led to a professional pluralism with competing views of professional practice. Schon believes that "technical rationality" (the dominant epistemology of practice), has most powerfully shaped professional thinking and the institutional relations of research, education and practice. He suggests that this professional practice of rigorous technical problem-solving, based on specialised scientific knowledge, has led to a hierarchical model of professional knowledge which has separated research from practice.

This separation has led to a "theory practice" gap with practitioners relying more on their intuitive practice in situations where technical knowledge does not appear to fit the uniqueness of their situation. Schon argues that there is therefore a need to explore the epistemology of practice implicit in the artistic, intuitive processes which some practitioners have brought to situations of uncertainty, instability, uniqueness, and value conflict. He identifies that in the workaday life of professionals they are dependent on a different type of knowledge to that created by technical rationality, namely a tacit "knowing-in-action". However, the central issue in the knowledge of skilful action lies in the failure sometimes to be able to express it - it is a "tacit knowing" which is embedded in action. Schon maintains that in practice, through a process of reflection-in-action, practitioners cope with uncertainty by reflecting on what they are doing in a unique situation and restructuring their understanding as a result. Thus the practitioner is not dependent on the categories of established theory and technique but constructs a new theory of the unique case.

Schon espouses that because of the crisis of confidence in professional knowledge there is a need to develop new ways of professional practice and research. First, he calls for the demystification of professional knowledge and second, he argues the need for qualified professionals to engage in critical self-reflection. Furthermore he argues the need for reflective research in which the researcher, by maintaining close collaborative

relationships with the practitioners, is able to gain an inside view of the experience of practice. From the above the links between reflective practice and action research can be noted and it is not surprising that they have been described as one of the same thing:

> *"This kind of joint reflection about the relationship in particular circumstances between processes and products is a central characteristic of what Schon has called* reflective practice *and others, including myself, have termed* action research .....
>
> ..... *Action research improves practice by developing the practitioner's capacity for discrimination and judgement in particular, complex, human situations. It unifies inquiry, the improvement of performance and the development of persons in their professional role. With respect to the latter it informs professional judgement and thereby develops practical wisdom, i.e. the capacity to discern the right course of action when confronted with particular, complex and problematic states of affairs."*
>
> (Elliott, 1991, p.50 and p.52)

Within nursing, reflective practice is being increasingly advocated (Clarke, 1986; George, 1987). The changes in nurse education have meant that whole institutions through their Project 2000 courses are committing themselves to reflective practice with the intention of developing "knowledgeable doers" (Benner, 1984). This wholesale emphasis on the importance of a different type of knowledge needed to inform professional practice requires an accompanying change in philosophical approach to research. Whilst currently not the case, it is my belief that action research will become increasingly important in nursing research and will be used, not only to develop knowledge, but in developing a new type of professional practice. A crisis in confidence in nursing research has been argued by Greenwood (1984). She suggests that approaches to nursing research reflect a fundamental misunderstanding concerning the nature of nursing which has resulted in findings that are perceived as irrelevant to clinical practice. She highlights the need for action research to remedy this problem by producing a type of knowledge more appropriate to practice. Greenwood criticises Hunt's (1981) account of why research findings are not put into nursing practice and claims that Hunt misses the crux of the matter, namely:

> *"Clinical nurses do not perceive research findings as relevant to their practice. And further, they do not perceive them as relevant to their practice because frequently they are not relevant to their practice."*
>
> (Greenwood, 1984, p.77)

In spite of its perceived relevance, action research continues to remain outside the mainstream of research in many disciplines. Sanford (1981) claims the separation of science from practice results from fragmentation of knowledge caused by a general tendency toward specialisation in modern science and scholarship. In contrast, action research depends upon multidisciplinary work and advances in technology which have moved away from this compartmentalisation of knowledge, with experts being trained for specific functions and working in isolation. One result of this compartmentalisation has been the poor application of research to practice. Sanford (1981) believes academics, through action research, could lead the way to better understanding of man and thus making meaningful improvements in society.

Whilst this chapter focuses on the merits of action research, there is clearly a need to use a range of research approaches to answer different questions in practice. However, a situation currently exists where the validity of action research is being questioned by groups holding widely different assumptions. Action research should not be evaluated from a positivist perspective. It has developed from a completely different philosophical basis and calls on others to question the validity of using more traditional approaches in the human sciences.

Having explored the meaning of action research in the context of new paradigm research and argued for the need for more action research to be done in response to the crisis of confidence in professional knowledge, the following section examines the way this philosophical shift to a new paradigm of research has profoundly influenced people's understanding of action research in both the fields of education and nursing. It also examines the changes in conceptual understanding of action research in education and following this similar changes in understanding are traced in nursing by critically examining action research studies in health care practice.

Education and nursing: following similar methodological pathways

McNiff (1988) traces the development of action research in education and shows how it has moved on from Lewin's (1946) functionalist approach, through an interpretive tradition and into a new paradigm perspective. Holter and Schwartz-Barcott (1993) trace similar developments in nursing, identifying three main approaches to action research namely the technical collaborative approach, the mutual collaborative approach and the enhancement approach. Whilst nursing is independently responding to new ways of developing knowledge to guide practice, it appears to be considerably influenced by texts

on action research within education. This chapter argues that although there are many similarities between the two practice disciplines of education and nursing, caution is needed in applying approaches developed in education directly to nursing as there are some important differences to consider.

Changes in the interpretation of action research within education

Whilst action research was first introduced into education by Corey's book *"Action research to improve school practices"* (Corey, 1953), it was not really applied in Britain until 1973 when the Ford Teaching Project (1973-75) (Elliott, 1982b), which involved teachers in collaborative action research into their own practices, was launched. This work was heavily influenced by Stenhouse's views of the teacher as researcher which had been developed through the Humanities Curriculum Project (1967-1972) (Stenhouse, 1975). Prior to this time methods of evaluation in education were very much interpretive accounts written from the perspective of the expert researcher (McNiff, 1988). The nineteen seventies in education had seen a movement away from the more traditional experimental approaches to evaluation with its inherent focus on outcomes to more process models of evaluation (Parlett and Hamilton, 1972). Process evaluations in schools, where practitioners inform outside researchers about the nature of their work, have naturally led to institutional self-evaluation with teachers being seen to be the best judges of their own practices (Simons, 1981). Carr and Kemmis (1986) identify several reasons why a change in approach was welcomed at this time by educationalists, not the least of which that practitioners were having to adopt a self-monitoring role to justify their own practices and action research was seen as an understandable and workable approach to the improvement of practice through critical self-reflection. This movement towards critical self-reflection clearly placed those involved in the change process as being equally involved in the research process too. Action research in education was seen as being concerned with the *improvement* of practice, the improvement of *understanding* of the practice by its practitioners and the improvement of the *situation* in which the practice takes place and thus the essential aims of action research was to *improve* and *involve* (Carr and Kemmis, 1986).

Following these changes in emphasis, formal schemes of action research based on Lewin's original concept emerged to guide practice. McNiff (1988) describes and criticises the formal schemes of Kemmis and McTaggart (1982), Elliott (1982a) and Ebbutt (1985) on several accounts. First, she criticises them as being inappropriately prescriptive, arguing that the use of rigid models denied the spontaneity and creativity which occurs in practice. Second, she argues that the models tend to be concerned with observation and description rather than explanation and as such are in themselves not

educational. In contrast, she stresses the need for practitioners to be able to formulate their own personal theories of education based on practice and suggests that research needs to have a self-generative capacity to allow for the more creative spontaneous episodes that occur in reality. She therefore proposes a "generative action research" that enables the practitioner to address many different problems at one time without losing sight of the main issue. She represents this visually as a three-dimensional spiral of action-reflection cycles. This three-dimensional spiral of action-reflection cycles, in some ways, best describes what happened in the present study which is concerned with a multidisciplinary approach to lay participation in care in hospital. A conscious decision was taken not to use a more prescriptive model as I wanted to take on a facilitative role and allow issues and problems to be dealt with as they emerged naturally from practice. However, whilst McNiff (1988) argues that there are important differences in approaches to action research within education, it could be counter argued that this is really a matter of semantics. If some of the formal schemes are seen as being limited, it is as much to do with their deficiencies in describing on paper the essence of what is meant by action research. For instance, there can be no doubt that Elliott (1991) shares the same philosophical understandings of action research as McNiff when she argues that the fundamental aim of action research is to improve practice rather than to produce knowledge and suggests that action research is a form of reflective practice.

In contrast Winter (1989) extols the usefulness of some of the schemes referred to by Elliott (1982a) and Kemmis (1985) in guiding action research studies in practice. His criticisms of such schemes are more concerned with the cursory treatment they give to the process of reflection. To Winter (1989), reflection is the crucial process by which we make sense of evidence. He argues that by ignoring this aspect, action researchers lay themselves open to being criticised by conventional researchers. He suggests that there are positivist echoes in some of the formal schemes of action research, such as, the collection of facts, the diagnosis of problems and the tendency for there to be a prescriptive sequence between theory and practice. He argues that reflection is needed to overcome the problem of action research being viewed by positivists as "biased" and "anecdotal". Winter identifies four practical problems in carrying out action research namely time, gaining new insights from small scale investigations, accessibility of action research procedures for practitioners and ensuring that what is discovered goes beyond an individual's beliefs, assumptions, and ideologies. He offers a solution by citing six principles for the conduct of action research namely reflexive and dialectical critiques, collaborative resource, risk, plural structure and theory, practice and transformation. Winter thus makes an important contribution to current understandings of action research.

Action research has been linked to Habermas's critical theory and critical social science (Habermas, 1972) and is used to delineate three types of action research: "technical", "practical" and "emancipatory" (Carr and Kemmis, 1986). Technical action research occurs when facilitators persuade practitioners to test out the findings of external research in their own practice. In practical action research, outside facilitators collaborate with practitioners to help them articulate their concerns, plan action, change practice and reflect upon the process and outcomes of that experience. Practical action research can be seen as a stepping stone to emancipatory action research. Emancipatory action research embodies the values of a critical social science as depicted by Fay (1977) and based on Habermas (1972):

> *"(Critical social science) ..... is clearly rooted in concrete social experience, for it is ..... explicitly conceived for the purpose of overcoming felt dissatisfaction. Consequently, it names the people for whom it is directed; it analyses their suffering; it offers enlightenment to them about what their real needs and wants are; it demonstrates to them in what way their ideas about themselves are false and at the same time extracts from these false ideas implicit truths about them; it points to those inherently contradictory social conditions which both engender specific needs and make it impossible for them to be satisfied; it reveals the mechanisms in terms of which this process of oppression operates and, in light of changing social conditions which it describes, it offers a mode of activity by which they can intervene in and change the social processes which are thwarting them. A critical social theory arises out of the problems of everyday life and is constructed with an eye towards solving them."*
> (Fay, 1977)

In emancipatory action research, the practitioner group takes joint responsibility for the development of practice, understandings and situations, and sees these as socially-constructed in the interactive process of life. In essence emancipatory action research is an empowering process for participants and engages them in the struggle for more rational, just, democratic and fulfilling forms of practice.

Thus it can be seen that action research has moved on from Lewin's conception in 1946. Whilst the action-reflection spirals may form the basis for many of the more modern day definitions, there are some important differences which are summarised by Hopkins:

> *"Lewin's concept of action research was (i) as an externally initiated intervention designed to assist a client system, (ii) functionalist in orientation, and (iii) prescriptive in practice. None of these features apply to what I assume to be the nature of classroom research by teachers which is characterised by its practitioner, problem solving, and eclectic orientation."*
> (Hopkins, 1985)

Carr and Kemmis (1986) suggest that Lewin saw participation as a matter of technique rather than as a matter of principle and was thus functionalist in his approach. Furthermore they question Lewin's idea that participants should be led to a more democratic life through action research and replace this with the view that participants should be enabled to make choices about their conditions of work and life. Finally, whilst Lewin recognises the contribution of action research to both practice and academia, Carr and Kemmis (1986) suggest the language used is positivistic and thus incompatible with modern approaches to action research.

Thus it can be seen that action research has undergone considerable development in conceptual understanding. Whilst less so in the social sciences, action research is currently enjoying popularity within the field of education. Lomax (1994) argues that action research is very different from social science research since the questions posed, approaches favoured and the criteria applied for judging research are very different. She sees action research as an educational practice for all those involved and contends that it is the most effective form of research for practitioners. Whitehead (1993) similarly views action enquiry as educational because it enables practitioners to see their practice as part of a living educational theory that is generated from their own critical enquiries. Action research is thus seen as a way of bringing about change in schools and is seen as a way of supporting the work of teachers through their professional development (Lomax, 1989). A Collaborative Action Research Network (CARN) exists which regularly publishes action research studies and organises conferences to debate relevant issues (Somekh, 1990). Action research is seen as the way to resolve the theory-practice issue. It is hoped that action research will allow the spread of a more reflective culture which will counter balance the technical rationality that underpins government policy-making (Elliott, 1991). In terms of it being an applied social science, nursing shares much in common with education, not only professionally but also academically and politically. The following section critically explores some of the action research studies that have been undertaken in health care and particularly hospital nursing. In so doing the conceptual changes in action research within nursing are noted. In conclusion a cautious note is added on the continued application of action research concepts from education to nursing practice.

Changes in the interpretation of action research within nursing

Holter and Schwartz-Barcott (1993) suggest that within the nursing literature there has been no systematic identification of or debate about the core characteristics of action research or the multitude of approaches or uses that have come to be associated with the methodology. They suggest that action research has had a parallel but independent development in England from the time Lewin formulated his ideas in the United States through to its development at the Tavistock Institute for Human Relations. In contrast to Lewin's social and experimental psychology, the group at the Tavistock Institute for Human Relations was an interdisciplinary group which had its theoretical foundations within psychoanalysis and social psychology. Since then various researchers working within organisation and management, education, health care, psychology and sociology have used Lewin's and the Tavistock Institute's work, while at the same time developing their own philosophical orientations to action research.

As discussed earlier Holter and Schwartz-Barcott (1993) identify three main approaches to action research in nursing - the technical collaborative approach, the mutual collaborative approach and the enhancement approach. The technical collaborative approach aims to test a particular intervention based on a pre-specified theoretical framework within a practical setting. The nature of the collaboration between the researcher and the practitioner is technical and facilitatory with the researcher being responsible for identifying the problem and a specifying the intervention. The interaction between the researcher and the practitioners is aimed at gaining the practitioners' interest in the research and agreement to facilitate and help with its implementation. Essentially such an approach produces predictive knowledge and the major thrust is on validation and refinement of an existing theory and hence is essentially deductive. In the mutual collaboration approach the researcher and practitioners come together to identify potential problems, their underlying causes and possible interventions. The practitioners gain a new understanding of their practice. However the changes tend to be connected to the individuals involved in the change process and therefore the interventions tend to be short lived. Knowledge generated from this approach is generally descriptive and inductive in theory development. The enhancement approach has the researcher raising questions about the underlying assumptions and values. It also involves practitioners in critically reflecting on their practice and brings to light the difference between stated practices underlying assumptions and unwritten laws which really govern practice. The emphasis here is on bringing to the surface the underlying value system, including norms and conflicts which may be at the core of the problems identified.

Thus these three approaches reflect the gradual change in thinking away from positivist and interpretive notions of science to the more modern understandings of action research which emphasise practitioners as researchers, the importance of self reflection and the development of a critical science through the empowerment of practitioners. The following section selectively reviews hospital based action research studies and attempts to categorise them in relation to the three main approaches to action research discussed in both the education and nursing literature. It demonstrates the difficulty of compartmentalising studies concerned with an approach to research, rather than a method. An approach has many different facets and not all facets naturally occur together. Each approach has its own strengths and weaknesses for any given situation. It is precisely for this reason that, an eclectic approach to action research is used in the present study. Given that nurse researchers appear to have been greatly influenced by developments in thinking in education, a note of caution is drawn on wholesale adoption of ideas from one discipline to another.

Studies using the technical collaborative approach

Holter and Schwartz-Barcott (1993) reference several action research studies in health care which have used this approach (Armitage et al., 1991; McCaugherty, 1991a; McCaugherty, 1991b). Given that the technical collaborative approach is generally associated with earlier approaches to action research, it would appear that the authors quoted by Holter have not engaged in the more recent methodological debates that have taken place in the action research literature (Reason and Rowan, 1981; Carr and Kemmis, 1986; Elliott, 1991; Whyte, 1991). It perhaps also indicates that these researchers have not read more widely than the nursing research literature and reveals a weakness in their work. For instance, McCaugherty (1991a) demonstrates a limited understanding of action research and his work is of questionable validity and Armitage et al. (1991) make dubious claims in their reporting, tending to focus on the outcomes of change rather than the process of trying to change practice.

McCaugherty (1991a) claims to have used action research when developing and evaluating a teaching model which aimed to improve the integration of theory and practice for first year students nurses. Within the study an experimental approach was used to assess the model using a static group comparison. The experimental group consisted of first-year students who worked on a ward on which the researcher carried out the teaching sessions three to four times a week. The control group consisted of first-year students from the same intake who worked on an adjacent surgical ward and who were not exposed to the model. Participant observation and semi-structured interviews with students, together with data record analysis, care plan presentations and spot checks were

used to monitor the change process. Over an eighteen month period, eight different action cycles occurred. Each cycle lasted for nine weeks and was used to develop and evaluate the teaching model. Spot checks were analysed qualitatively and systematically for evidence of the student's ability to reason and display depth of understanding in relation to the patients they were nursing. Twice as many experimental students fell into the "good" category and twice as many of the control group fell into the "poor" category. The study has questionable validity. First, it claims to be qualitative and is said to be based on action research and illuminative evaluation. It is not clear in what way this is an action research study. The nature of the collaboration is not made explicit. There is said to be a cyclical approach which allowed for progressive focusing. However, what was focused upon and what was changed as a result is also not made clear. Second, although described as a qualitative study it appears to be more quantitative in nature, using an experimental design and attempting to measure change. Third, the researcher knew which groups students belonged to and had a familiar relationship with the experimental group which might have affected their responses.

Armitage et al's. (1991) work can also be criticised for not appearing to have engaged in more recent understandings of action research. The authors conducted an action research study which aimed at implementing primary nursing in two long-term psychiatric rehabilitation and continuing-care wards and to investigate the effects of the intervention on the quality of nursing care provision. The design comprised a quasi-experimental and ethnographic evaluation of non-equivalent groups. A package of measures together with a number of peripheral indicators were used before primary nursing was introduced on each ward and again after primary nursing had become established. The results showed that the implementation of primary nursing led to nurses being more accountable for care, residents were seen to be more self-sufficient and independent and wards had an improved environment for care and rehabilitation. This innovation took place over a period of six months only and it is therefore surprising that the researchers felt able to claim that in this time they had been able to introduce such effective primary nursing.

The impression given by the researchers is that the innovation was a success because of the results of the observations of patient care and clinical meetings, nursing staff questionnaires concerned with job satisfaction (Warr et al., 1983), attitudes to the nursing process (Bowman et al., 1983; Everden, 1983), and nurses' views on their role (Rump, 1979) and their opinions on the atmosphere of the ward (Moos, 1974); together with pre and post-change audits of standards of care by expert and peer groups using a 155-item checklist and a retrospective analysis of nursing records (Kemp, 1986).

However, closer examination of the study report reveals that many of the findings showed "not much difference for both wards, for the pre-change and post-change scores" (Armitage et al., 1991). The report also fails to be critical of the limitations of using quantitative tools to measure change and reflects neither on the difficulties of using self report questionnaires to measure change nor on the problems of repeating questionnaires within a relatively short space of time. By focusing so much on trying to measure the outcomes of change the researchers fail to share any of the process issues so fundamental to understanding practice which demonstrates a limited view of action research.

Other studies can also placed under Holter and Schwartz-Barcott's (1993) heading of the technical collaborative approach such as Wieland and Leigh (1971) and arguably Towell and Harries (1978). These studies pre-date current thinking on action research had not been explored and unlike the more recent studies by Armitage et al. (1991) and McCaughterty (1991a) were considered progressive in their time.

Wieland and Leigh (1971) describe the first hospital based action research study (Hospital Internal Communications Project) which took place following the publication of "Standards for Morale", a report of research undertaken in Lancashire hospitals in 1964 and which recommended experiments in action learning to improve hospital effectiveness (Revans, 1964). Controversy surrounds this report for its suggestion that the mean length of patient stay was related to staff morale. Nonetheless it is influential both as a textbook for students of hospital administration (highlighting issues and problems relevant to hospital life), and in establishing action research as an appropriate means for changing health care practice. In the literature, action learning and action research are sometimes used interchangeably, but Revan's main concern was that hospitals should examine their own actions and improve their practices.

Over a period of 4 years, the Hospital Internal Communications Project (Wieland and Leigh, 1971) involved several London hospitals in planning and implementing change programmes directed at improving the day-to-day functioning of their organisations. In total, thirty-eight individual projects were completed, covering a wide variety of topics including staff dining arrangements, the scheduling of operating theatres, appointment systems for out-patients, messenger services, patients' attitudes to clinical ward rounds, and the workload of medical social workers. Participants for these studies were drawn from the medical, administrative, and nursing staff who worked together with a central team of social scientists. These social scientists were responsible for assisting in the planning and conducting of projects and also for helping participants in evaluating the results and in reporting back to colleagues. The focus of their inquiries was on a general

understanding of the obstructions and ambiguities of the communication system within hospitals.

It is interesting to note that this action research project, whilst encouraging active participation amongst those being researched, nonetheless drew heavily on a "top down", authoritarian approach which emphasised the value of objectively measuring change as advocated in positivist approaches to science. The project was essentially prescriptive in nature suggesting to participants that poor morale in hospital was a consequence of (among other things) inadequate administration. The initiators of the study also began by suggesting that members of hospital staff should be released for six months to learn the methods they might need to examine the effectiveness of their own management and advocated that once back at work, participants should be prepared to dedicate one third of their work time for using these newly acquired methods to evaluate their practice. Furthermore, participants were expected to share their findings not only with their peers but also with other organisations, such as universities. Such a prescriptive approach alienated some hospitals from taking part, although eventually ten did agree to participate.

Another feature of the project, which locates it in a more traditional action research framework, was the inclusion of special project teams to independently evaluate the different initiatives. Their function was to act as auditors, "hearing and seeing all", but contributing nothing in return. This is a far cry from more recent interpretations of action research and understandably led to some tensions within the project teams (Craig, 1976). Furthermore, whilst ten hospitals were put forward for the project by their senior management, it is doubtful that the hospital teams actually involved in changing their practice were indeed true volunteers. Another more traditional approach to action research can be seen in the evaluator's particular interest in measuring outcomes (Wieland and Leigh, 1971). Despite the limitations in this earlier work (being inappropriately based on positivist notions of science), it was nonetheless an important catalyst for change, not only in some London hospitals, but internationally, in a variety spheres of work (Revans, 1976).

Arguably, Towell's (1978) work might be placed in the technical collaborative approach, although it is interesting to note that he was clearly aware of the changes in thinking as regards methodological approaches to evaluation of innovation at that time and actively chose to take a middle line as the following quote illustrates:

> *"In evaluating innovations, some proponents have favoured what might be described as a 'before and after' assessments based essentially on experimental designs; others have argued for 'illuminative evaluation' (see Parlett and Hamilton, 1972) focusing rather on the processes by which change occurs and more influenced by social anthropological approaches to field research. We think it possible however to suggest an intermediate evaluation strategy, which combines a concern with understanding the complex processes involved in the interaction between an innovatory project and its host institution with appropriate attention to evidence on the nature and benefits of particular changes."*
> (Towell and Harries, 1978, p.18)

Towell and Harries' (1978) study stemmed from previous research which had examined practice and argued the need for an action research approach to facilitate change (Towell, 1975). The central theme to Towell's study was that innovation should be developed from within and as such took a "bottom up" approach to change and therefore possibly places him more in line with Holter and Schwartz-Barcott's (1993) mutual collaborative approach. However, there are aspects of the study which might be criticised for being prescriptive in nature. Within the study a social research advisor was appointed to assist hospital staff in identifying, investigating and tackling problems arising in their day-to-day work. The social research advisor had close links with the Tavistock Institute of Human Relations and had therefore probably been influenced by the work of Lewin (1946). Following on from Lewin's work, a "social systems approach" to change was developed at the Tavistock Institute of Human Relations (Menzies, 1960; Sofer, 1961; Miller and Rice, 1967) and this was used in the Hospital Innovation Project (Towell and Harries, 1978). It could be argued that once again this led to a prescriptive approach to monitoring change. Fundamental to this approach is a commitment to action research. However, it also specifies a particular theoretical stance in developing the project ideas, focusing on a special way of analysing the structure of the health care organisation and drawing heavily on psycho-dynamic interpretations of group and organisational processes. It could be viewed as a highly structured approach to action research and therefore less in tune with current interpretations.

Despite its highly structured approach the Hospital Innovation Project (Towell and Harries, 1978) did demonstrate the possibility of more fully utilising the potential contribution of staff at all levels in achieving informed innovation. It allowed staff to share their experiences through honest accounts and rather than making sweeping claims, invited the reader to judge the relevance of these accounts in respect of their own situation. As with the Hospital Internal Communications Project (Wieland and Leigh,

1971), the work stimulated further research in a variety of settings but led to the realisation that a pre-determined and centrally controlled dissemination strategy was inappropriate for action research of this kind. Instead it was recognised that staff needed to define their own situation and discover for themselves their capacity to bring about change (Towell and Harries, 1978).

Other action research studies in hospital settings have tended to be smaller in scale than those already discussed. However, as within the field of education, a change in approach to action research can be detected in these studies. The following section examines some studies which could be classified as having adopted the mutual collaboration approach.

Studies using the mutual collaboration approach

Holter and Schwartz-Barcott (1993) have identified examples of the mutual collaboration approach in the work of Smith (1986) and Webb (1989). As stated earlier it is very difficult to neatly place studies in one category or another when dealing with an approach to research rather than with a method. There are elements of Smith's (1986) work which might indeed be perceived as mutual collaboration. In her study she attempted to work closely with participants to facilitate changes towards improving the quality of life for patients in a hospital setting. She was not attempting to control variables through an experimental design with quantitative measures. However, it could be argued that her approach was very much influenced by earlier understandings of action research and, because of the similarities between her and Towell and Harries' (1978) work, she had an element of prescription in her design. Smith's work was based on the work of social scientists from the Tavistock Institute of Human Relations and it could be argued that this may have biased her findings. For instance, she used social systems and psychoanalytic theories to understand why resistance was encountered to change in a geriatric setting. She related the strength of this resistance to change to the specific stresses of providing care for the ageing and dying patients. Thus Smith draws quite heavily on Menzies' (1960) earlier work which found that professionals cling to routine tasks as a social defence mechanism against high levels of anxiety and stress caused by the awareness of human suffering in the professional-patient relationship.

To some mutual collaboration appears to be concerned with the extent to which the researcher is perceived to be an "insider" or "outsider" (Titchen and Binnie, 1993b). In their article the authors highlight tensions and problems with insider and outsider models and advocate a preference for their own models of action research, namely the "double-act" and the "collaborative group" partnerships. The insider model combines the

roles of actor (clinical leader with authority for initiating and managing change), change agent and researcher. Titchen and Binnie (1993b) identify various action research studies in nursing which have taken this approach (Pearson, 1985; Fitzgerald, 1989; Batehup, 1991). In contrast, the outsider model is described as the action researcher being someone from outside the setting and thus having no authority in the situation. They equate this with someone who has a diagnostic function and who feeds back observations to the participants, but who does not initiate or carry out the change. They cite several action research studies in this category (Lathlean and Farnish, 1984; Smith, 1986; Hunt, 1987; Webb, 1989; Armitage et al., 1991; Wilson-Barnett, 1990; Meyer, 1991b). Titchen and Binnie (1993b) fail to see that being an insider or an outsider very much depends on relationships. For instance, an outsider researcher may not have authority to initiate and carry out change, but may have more influence than an insider researcher with poor interpersonal skills. Titchen and Binnie criticise both insider and outsider models and advocate their own approach, namely the double-act and the collaborative group. However it is unclear how these are any different to the "outsider model" which they heavily criticise. In their action research study on which their model is based, one of the researchers, the "actor," had a senior management role and was perceived to be the change agent. The other was an educationalist and researcher with a physiotherapy background and took on the "researcher" role within a facilitative partnership. They developed five strategies to implement and evaluate the introduction of Primary Nursing. These strategies included: introducing innovation and facilitating change; helping practitioners research their own practice; facilitating professional learning and reflective practice; democratising health care through the emancipation of nurses from the traditional nursing hierarchy and the role of doctor's handmaiden; generating and testing theory. Whilst they claim success in using this model; success appears to have depended more on the personalities of the researchers, their relationships, and shared values than on a specific formula that could be replicated by other researchers.

There appear to be other limitations in Titchen and Binnie's model of action research. For instance, the change agent in the study appears to have had substantial power at various levels in the organisation and this raises issues about the extent to which participants in the study felt under pressure to conform to the project ideas. The collaborative nature of their study can also be further questioned, in that some participants were made to feel like "outsiders" due to the actor and researcher's close relationship with each other. Whilst this closeness is acknowledged in their work as being potentially dangerous in terms of confusing personal confidences with legitimate data and of being unquestioning of the other's thinking and behaviour, it is nonetheless

rationalised through advocating reflexivity and does not prevent them from proclaiming this particular approach as an ideal model of action research (Titchen and Binnie, 1993b).

Titchen and Binnie's (1993b) paper can also be criticised on account of their narrow understanding of what constitutes success in action research. The authors appear to judge the "success" of the reviewed studies in terms of whether the researcher's original aims were achieved. It is argued that success in action research should be measured in terms of what has been learnt from the experience of practice. It is not uncommon in this type of work for practitioners to wish to go off at a tangent to explore unanticipated phenomena. However, this should not viewed as "unsuccessful" research.

The issue of collaboration is nonetheless an important one. Some studies do appear to have had preconceived ideas about what the intended change should be. For instance, Fretwell (1982) used an action research approach to increase the awareness of ward sisters of the implications of their teaching role. The study aimed to familiarise ward sisters with their responsibility to satisfy the educational needs of learners, with a view to improving the quality of patient care. It intended to do this through a training programme which would enable sisters to fulfil their teaching role. Following a pilot study, which was viewed to be a failure judged on the lack of progress, a larger study involving ten wards in two districts was implemented. It is not clear from the study report what changes were made and how these were facilitated. However, it would appear that the researcher and participants may have had different interests in mind. Once again the study appears to have had more of a prescriptive approach to change in that the researcher had a preconceived view on how the ward should develop in order to improve practice. The study concluded that participation by individuals is not sufficient in itself to bring about change. Instead, the author argues, attention needs to be paid to creating a supportive environment for change. Whilst it can be argued that a supportive environment for change is clearly needed, the resistance to change may have been as much due to the participants having to work with findings from an earlier study (Fretwell, 1978) rather than identifying issues for themselves. In other words the project may have been too prescriptive and the participants may not have owned sufficiently the project ideas.

It is interesting to note that the passage of time has not only seen action research studies moving towards closer collaboration with participants, but also the evaluative focus moving away from quantitative measures to more qualitative approaches (Meyer, 1993). For instance, Lathlean and Farnish (1984) have used action research to develop and evaluate a training scheme for ward sisters which involved two researchers working

together with a team of practitioners in two hospitals between 1979 and 1983. The project was conducted in a series of overlapping stages, and exhibits the cyclical process of issue identification, implementation of change, data collection, consideration of the effects of action, further change and evaluation with the researcher collaborating with practitioners in the development of the scheme. Illuminative evaluation strategies (Parlett and Hamilton, 1972) have also been used to monitor the process of change, with feedback occurring at all points to those within such a training scheme, and to the committees set up to oversee the scheme as well as to funding bodies (for example, King's Fund, DHSS). The methods used to collect data included observation, open-ended and structured interviews, questionnaires and measurement tests of the competence of ward sisters. Illuminative evaluation relies on triangulation of data (Jick, 1979) and this marked a movement towards the use of qualitative approaches to monitor the process as well as the outcome of change. Whilst the study is categorised as an example of "mutual collaboration", the nature of the collaboration is unclear. It is questionable as to whether those within the training scheme shared the same interests and goals as the various committee members, set up to oversee the scheme and also the representatives of the funding bodies. Given that the researchers were reporting back to all these different people, with possibly varying and conflicting agendas, it is unlikely that mutual collaboration existed. Instead, the researchers appear to have acted more in the role of expert consultant and given the involvement of the King's Fund and its interest in the role of the ward sister at this time are likely to have held strong views on how the participants in the scheme should be professionally developed. In this sense the study sounds to be more prescriptive than collaborative.

Webb (1989) also used an action research approach to develop nursing and management skills on a hospital ward in order to improve both the quality of patient care and student nurse learning. The author's intention was to use the "development ward" as a base for training registered nurses in nursing and management skills in order that practice might be developed on other wards. The study differs from earlier work (Lathlean and Farnish, 1984) in that the researcher intended to work alongside trained nurses on their own wards to help them evaluate their practice, plan and implement change, and evaluate its effects, in preference to employing special ward sisters and preceptors. Webb (1989) aimed to demonstrate that "ordinary" nurses could achieve change when provided with advice and support and hoped that the findings would contribute to the development of action research methodology in nursing. This level of collaboration with participants could be viewed as a significant movement away from a consultancy approach towards practitioner research.

The study used a range of both qualitative and quantitative methods to gather data and included participant observation, interviews and questionnaires. Of note is that Webb's (1989) study makes a unique contribution to action research in nursing by openly discussing her feelings as an action researcher, identifying her self doubts and insecurities. This might be viewed as one of the earlier self reflective inquiries in nursing research. Webb's stance as a feminist researcher allies itself to the self reflective inquiry movement in education. As such her study could be well placed in Holter and Schwartz-Barcott's (1993) category of the enhancement approach.

Studies using the enhancement approach

It is suggested by Holter and Schwartz-Barcott (1993) that to date there are no studies in nursing using the enhancement approach to action research. Interestingly, since this publication Waterman (1994) has reported on a study which uses a reflexive model of action research to develop ophthalmic practice in two out -patient settings. Whilst Waterman does not claim to have engaged in emancipatory action research, she nonetheless includes three elements of it in her work namely: the notion that reflection would inform action, the democratic collaborative relationship between researcher and participants and the idea that education should lead people to become reflective and critical which in turn helps them to be more independent and in control of their lives.

Waterman's (1994) thesis contributes to and expands the debate on reflexive research in nursing. Reflexive researchers attempt to account for their interpretations of the data, and in doing so, analyse their effect on the research process. Waterman's work is clearly influenced by philosophical writings in a variety of disciplines and she makes a useful critique of Lewin (1946)'s notions of action research, Habermas (1972)'s critical theory, Reason and Rowan (1981)'s co-operative inquiry and Carr and Kemmis (1986)'s emancipatory action research. Whilst Waterman's philosophical discussion perhaps could have been expanded, nevertheless she does attempt to synthesise modern day understandings of action research.

Aspects of Titchen and Binnie (1993c)'s work, described earlier, can also be seen as a form of enhancement research. They document and reflect upon the complexity of establishing new nursing roles, the devolution of authority and the shift in power relationships within the ward team, plus the confusion and pain caused by role ambiguity. Titchen and Binnie (1993c) claim their study enabled staff nurses to develop personally and professionally, through articulation and theorisation of their practice as well as what was happening to them. They suggest that individuals were helped to see problems as interesting, and not overwhelming. The nurses involved in the study were reported to

have felt empowered by thinking through the problems, looking for achievable solutions, devising plans and later carrying them out successfully.

Note of caution

Whilst it is difficult to place studies into specific categories, there are a variety of action research studies in nursing which draw on different philosophical perspectives. Titchen (1993), in a way similar to Holter and Schwartz-Barcott (1993) explores the philosophical stances (positivism, idealism and realism), research paradigms (empirico-analytical, interpretive and critical) and the relationships between them. However, she locates action research as a methodology in the interpretive and critical paradigms. Strictly speaking action research should be viewed more as an approach to research which can incorporate a variety of methodologies including quantitative methods normally associated with positivist science.

Meyer (1993) briefly addresses the changes in conceptual understanding of action research and draws parallels with changes in thinking in education. It is argued that the literature on action research in education has influenced nurse researchers understanding of action research. However, whilst this is appropriate because of the similarities between the two practice disciplines, a note of caution needs to be drawn on wholesale adoption of ideas from one discipline and application to another. Greenwood (1994) notes the growing interest in action research in nursing and suggests that it is important to engage critically in the methodological debates. However, she advocates caution in uncritical adoption of ideas from one discipline to another. She recognises that action research generates and tests action theories in practice and as such is developmental for the practitioners involved. She also notes that this process can be emancipatory for practitioners and suggests that this is not always made explicit in nursing action research studies. She argues that insufficient attention is given to the psycho-social costs of emancipatory action and believes that this has important implications for nurses. She argues that what might be appropriate for educational settings might not be suitable for health care practice. For instance, she suggests that whilst teachers enjoy autonomy in their classrooms (which enable them, without risk, to implement small-scale innovation), nurses work as part of a larger multidisciplinary team and as such are likely to incur psycho-social costs when dealing with others who are more, or less, powerful than themselves. The present study lends support to this argument and it is interesting to note that other nursing action research studies have encountered problems in changing practice due to issues of power (Webb, 1989; Johns and Kingston, 1990; Titchen and Binnie, 1993a; Waterman, 1994).

Waterman (1994) also has concerns about the practicality of translating some ideas from education to nursing. Given the constraints that practitioners are often working under, she questions whether practitioners have the time, inclination or ability to reflect and theorise in practice and argues that texts do not address how reflective practice can be achieved. More recent writings on action research (Elliott, 1991) advocate that the practitioner should be the researcher who appears to devalue the contribution of academic researchers. The arguments in support of this stance are very persuasive, but in practical terms nursing may not be ready for this kind of approach. Only in recent years has there been an emphasis on reflective practice within nursing and so for many the concept of reflective practice remains quite alien. Furthermore, those individuals interested in research and who are in a position to apply for research funds, are often graduates. It could be argued that at this point in history it is only through such academic researchers, acting in professional development roles, that other practitioners will have the opportunity to engage in action research. It should also be noted that action research may not be popular with those funding bodies who evaluate research proposals using positivist criteria. Again the academic researcher might have an important role to play in educating people at all levels about the value of practice based, collaborative research.

Other issues also need to be taken into consideration. In health care practice, as this thesis explores, medical domination remains an issue and the concept of interprofessional work is in its infancy. The development of health care practice relies on multidisciplinary teamwork and it could be argued that until there are better working democratic practices in health care, action research will be difficult to initiate. Somekh (1994) , an educationalist working with action researchers in a variety of disciplines, notes the effect of occupational cultures upon action research methodology and supports the notion that its definition should be grounded in the values and discourse of the individual or group rather than in any particular methodological school of thought. She argues that action research methodology needs to be sensitive to context and flexible in its approach.

Clearly there are potential differences between educational and health care settings which warrant caution in adopting approaches from one discipline and applying them to another. That view is not intended to underplay the invaluable contribution that education has made in developing the thinking of nurse researchers. However, perhaps the time has come for nurses to develop their own forms of action research by being eclectic and drawing on the strengths and noting the weaknesses of all the different approaches to action research in relation to their own particular practice situations.

SUMMARY

This chapter has explored the meaning of action research through a historical review of the changes in conceptual understanding both within education and nursing practice. Action research has been described in the context of new paradigm research. and its legitimacy as a science in contributing to social knowledge has been discussed. Drawing on the arguments of Schon (1983) concerning the crisis in professional knowledge, the need for action research studies within the practice discipline of nursing has been explored. Finally, hospital based action research studies in health care and nursing in particular have been critically examined in view of the changes in interpretation of action research. In conclusion a cautious note has been drawn about the differences between education and nursing and the need to be selective in adopting approaches to action research from another discipline. Eclecticism has been advocated and reflected in the approach taken to action research in the study. The following chapter explores the methods of data collection used in the study in the context of the eclectic approach taken.

CHAPTER 5

METHODS

INTRODUCTION

The methodological approach taken in the study and discussed in this chapter does not follow a specific model of action research as described in Chapter 4. An eclectic stance has been adopted, derived from a range of approaches.

The eclectic approach to action research is described in terms of its democratic impulse, collaborative nature, evaluative methods and its contribution to the body of knowledge. Fuller details are then presented of the study's aims and objectives, the participants involved, data collection tools and methods of analysis. In Chapter 1 a description of the context of the research and a chronological account of what happened during the period of the study was offered. This chapter serves to provide the reader with a more detailed account of the methods used to generate the data.

ACTION RESEARCH APPROACH TAKEN IN THE STUDY

This section describes the eclectic approach used in terms of its democratic impulse, collaborative nature, evaluative methods and its contribution to the body of knowledge.

Democratic impulse

Action research is concerned with an intervention in practice to bring about change and improvement (Elliott, 1991). The study focused on the issues and problems of trying to change health care practice in such a way that patients and their family and friends might be more involved in their own care in hospital. Underpinning such an approach to care are the notions of "self help", "demedicalisation or deprofessionalisation", and "democratisation" (McEwen et al., 1983). Thus the democratic impulse in this action research study was not only concerned with empowering practitioners to systematically examine and change their practice, but also with empowering lay people to be more in control of their health care. It engaged participants in the struggle for more rational, just, democratic and fulfilling forms of health care. The empowerment which action research produces is significant as it is concerned with enlightenment and the organisation of change. By working collaboratively with a multidisciplinary team of health care professionals, it was possible to uncover contradictions and conflicts in practice which stood in the way of change. In

so doing practitioners were empowered to address issues which had previously been hidden and through this process of enlightenment were given the opportunity to change. Thus, dealing with issues in the reality of practice, it was possible to explore why health professionals claimed to be positive about lay participation in care but at the same time appeared reluctant to initiate such an approach in practice. Furthermore, through working closely with participants it was possible to gain insight into the constraints of the everyday practices which imposed limits on what could be achieved in terms of change. It was also possible to understand better some of the contradictions between current health care policy and practice. Thus the study can be seen as a form of critical social science which is similar in some ways to the "enhancement" (Holter and Schwartz-Barcott, 1993) or "emancipatory" (Carr and Kemmis, 1986) action research approach. Whilst it clearly has some elements in its approach which locate it as a form of emancipatory action research, the study does not embrace all elements. In particular, whilst it was designed to empower both health care professionals and lay people in order to change fundamental practice, the reluctance or inability of health care professionals to collaborate more in the project ideas suggests that it also shares characteristics with the "mutual collaboration" (Holter and Schwartz-Barcott, 1993) or "practical" (Carr and Kemmis, 1986) approaches to action research. This is explored further in relation to the collaborative nature of the action research study.

Collaborative nature

Action research is carried out by people directly concerned with the social situation that is being researched and is concerned with the practical questions arising in their everyday work (Elliott, 1991). A pre-condition of action research is that the participants perceive a need to initiate change. Criticism might be levelled at the study in that its focus arose from previous research rather than from practice. However, it took a "bottom-up" approach to change and began by systematically identifying a group of volunteers who were willing to examine their practice and initiate changes which would ultimately facilitate lay participation in care. As a researcher and facilitator of change I tried not to influence the change, but aimed to take my lead from the participants. Thus through mutual collaboration I encouraged them to participate in the project ideas at whatever level they wished and assisted them in gaining new understandings of their practice. In this way the study resembled practical or mutual collaboration action research. However, this type of action research is normally undertaken by "outsider" researchers and it could be argued that in this particular study, despite unsubstantiated claims to the contrary (Titchen and Binnie, 1993), my role as a researcher was that of an "insider". In going back to an institution where I had been known previously and negotiating access to a ward that invited me to be part of the multidisciplinary team, I believe I established an "insider" role. This role was further developed by working

alongside participants in everyday practice for a period of at least one year and I have every reason to believe that, in spite of the upheaval in group dynamics that resulted from the status quo being challenged, I was professionally and socially integrated into the team. As discussed previously, practical or mutual collaboration action research can be seen as a stepping stone to emancipatory or enhancement research (Carr and Kemmis, 1986) and in many ways the present study draws on aspects from both types of approach. However, it can also be seen to have characteristics similar to "technical" (Carr and Kemmis, 1986) or "technical collaborative" (Holter and Schwartz-Barcott, 1993) action research in its evaluative methods which are discussed in the following section.

Evaluative methods

As will be seen from the section on methods used to generate findings, an eclectic approach to the research was adopted which included quantitative and qualitative approaches. Whilst qualitative methods bear closer resemblance to practical or mutual collaborative and emancipatory or enhancement approaches used in action research, quantitative methods are more naturally associated with technical or technical collaborative approaches to action research. The present study used quantitative methods not only as a means of collecting some of the data but also to add a further dimension to the qualitative method of data analysis. This was done for a variety reasons. First, the use of some quantitative structured questionnaires measuring various aspects of the ward characteristics allowed for ease of data collection and facilitated more accurate comparison of data over time. Action research can be very time consuming as it focuses not only on data collection but also on changing practice. Therefore being pragmatic is essential. Second, the use of structured questionnaires to assess participants' views of lay participation in care allowed for data triangulation (Jick, 1979), which in turn led to a greater depth of understanding of the health professionals' perceptions of such an approach to care. Third, by mixing the methods it was predicted that the weaknesses and limitations of the different types of methods would be counter balanced (Brewer and Hunter, 1989). Fourth, whilst all the qualitative data were analysed for themes, a quantitative dimension was added to the data analysis by enumerating the number of times themes occurred for each group of participants. This allowed for systematic comparison between groups and was justified on the basis that the participants themselves were interested in these kinds of data, in that they were more familiar with quantitative than qualitative approaches to research. Somekh (1994) identifies the need for action researchers to be pragmatic and advocates that action researchers should be sensitive to the occupational cultures in which they work and adapt their research methodology accordingly. She even cites the need for nurse researchers in particular to be methodologically rigorous in order to establish credibility with the medical profession. Given that the study was of a multidisciplinary nature it seemed appropriate to include

quantitative approaches in the evaluative methods. However, it should be noted that other evaluative methods used in the study, for example, self reflection, semi-structured interviews, participants observation, were atypical of the more traditional technical or technical collaborative approaches to action research. Hence the present study can be viewed as an amalgamation of approaches which, whilst being essentially eclectic and pragmatic in nature, also attempts to be sensitive to the occupational culture of the participants. It could be argued that the pragmatic approach taken makes the findings relevant only to the occupational culture sampled for the study. However, the following section explores the way in which the study might contribute to the more general body of knowledge.

Contribution to the body of knowledge

Generalisations made from action research studies are different to those made from experimental research studies and should not therefore be judged weaker or stronger by comparison. Action research offers a surrogate experience and invites the reader to underwrite the account, by appealing to his tacit knowledge of human situations. The truths contained in a successful report are assumed by the shock of recognition (Carr and Kemmis, 1986). Simons (1971) cautions the need for reports to be authentic, detailed, rigorously accurate and impartial. She highlights the importance of making the experience of innovation accessible to both public and professional judgement. Through systematically feeding back findings throughout an action research study it is possible to check the accuracy of the account with participants, however the relevance of the findings to any other practice situation ultimately rests with the reader. However, this thesis argues that the use of triangulation in exploring health professionals' attitudes to lay participation in care raises certain questions about the validity of previous research carried out in this area. It is thus possible to add to the body of general knowledge by throwing into doubt claims, held previously.

Thus the present study draws on a range of approaches to action research including aspects from the technical, practical and emancipatory models (Carr and Kemmis, 1986). The eclectic approach taken is deemed more suitable to health care settings. The thesis argues that as yet health care practice is not ready to focus on the more emancipatory approaches to action research that are advocated in the education literature. The lack of democratic practice within the health care team, the lack of time available for practitioners to become more involved in a self reflective manner, and the lack of methodological understanding inhibits the usefulness of the more modern approaches to action research being applied to health care settings.

Having given a rationale for the eclectic approach taken to action research in the study, the following section gives fuller details of the study's aims and objectives, participants involved, data collection tools and methods of analysis.

METHODOLOGICAL DETAILS

This section begins with a discussion of the study's aims and objectives. It is interesting to note that they were written as part of the research proposal and not all of them were fully realised.

Aims and objectives

The aim of the project is to describe the process and impact of introducing lay participation in care within the context of a ward environment. The objectives are listed below.

1. To establish which wards wish to participate in an action research study aimed at introducing lay participation in care.
2. To ascertain what is understood by lay participation in care.
3. To describe how patients, their close family and friends and health professionals feel about lay participation in care.
4. To determine how lay participation in care can be systematically introduced in a ward environment.
5. To identify the effects of introducing lay participation in care on a ward environment.
6. To monitor changing roles of health professionals on introducing lay participation in care.
7. To consider whether any specific groups of patients respond better to lay participation in care e.g. age, sex, culture, disease processes, social class and education.
8. To specify the effects of introducing lay participation in care on the wider environment of the hospital.
9. To highlight the implications of introducing lay participation in care within a ward environment for community care following discharge.

Although the study set out with the above mentioned aims and objectives in mind, action research is led by the participants and therefore the researcher has to take a flexible approach to data collection. Data gathered were mainly concerned with the health professionals' perceptions of lay participation in care and with the challenges they encountered when trying to change practice. However, because little lay participation in care was actually translated into practice, it was not possible to ascertain the lay

perspective, nor comment on whether particular groups of patients responded better to the concept, nor monitor the effect of its introduction on the wider environment of the hospital and the community. Nevertheless, given the social trends towards individualism and the constant flux of change within the health service, the study's findings are of direct relevance to all those working in health care practice and policy.

So that the reader may judge the relevance of these findings for themselves in relation to their own practice situation, the following section summarises details of the participants. Further details of the context in which the study took place can be found in Chapter 1.

Participants

The study took place on a general medical ward in a London teaching hospital and the participants consisted of the various members of the qualified multidisciplinary team who were either present throughout or came and left during the one year period of the study (see Appendix IX). Of these qualified multidisciplinary team members formal data, using interviews and questionnaires, were gathered from nurses, medics and paramedics (see Table 1).

Table 1: Members of multidisciplinary team from whom formal data (interviews and questionnaires) were gathered

Qualified Nurses	No	Medics	No	Paramedics	No
Clinical Nurse Manager	1	Consultant	2	Dietician	2
Charge Nurse	1	Senior Registrar	2	Occupational Therapist	3
Registered Nurse	16	Registrar	2	Pharmacist	1
		House Officer	8	Physiotherapist	3
				Social Worker	1
				Speech Therapist	3
Total	**18**		**14**		**13**

During the course of the study fifty three nurse learners commenced work on the ward (twenty three third year learners, twelve second year learners and eighteen first year learners) and whilst they were not considered to be active participants in the study due to their transience, some data were gathered about their perceptions of lay participation in care. Some contextual data were also gathered on their perceptions of the ward as an environment for learning and for giving patient centred care. During the study data were also gathered from eight senior nurse managers (district nursing) who were identified as key informants (Field and Morse, 1985) on the subject of lay participation in care in the community. It was suggested that the community nurses should be interviewed because

first, they needed to be kept informed of the changes on the ward to ensure continuity of the project ideas in the community and second, because they were likely to have some interesting thoughts on how people might be better prepared for discharge in relation to participating in their care.

Analysis of interview data showed that most of the medics and half of the qualified nurses had trained at the hospital in the study. This was in contrast to the paramedics who had either trained in another London hospital or in a hospital outside London (see Table 2). The participants were relatively junior with approximately a third proportion being qualified for less than six months and the majority being qualified for less than two years and only a few being qualified for more than five years (see Table 3). Half of the participants and in particular the majority of nurses were either in their first or second post since qualification (see Table 4). Furthermore a sizeable proportion of the participants had no experience of working in any other hospital apart from the one in which the study took place (see Table 5).

Thus in general terms the participants were rather junior and were not in a position to draw on the wider experiences of other hospital practices when considering lay participation in care.

Table 2: Participants' training hospital

Training Hospital	No. of M	% of M	No. of P	% of P	No. of N	% of N	Total No.	Total %
SH	10	72	0	0	9	50	19	43
OLH	2	14	6	46	3	17	11	24
OH	2	14	7	54	6	33	15	33
Total	14	100	13	100	18	100	45	100

SH: Hospital under study OLH: Other London hospital OH: Other non London hospital
M: Medics; P: Paramedics; N: Nurses

Table 3: Participants' length of time since qualification

Time since qualification	No. of M	% of M	No. of P	% of P	No. of N	% of N	Total No.	Total %
<6mth	6	43	2	15	6	33	14	31
6 mth - 1yr	2	14	2	15	1	6	5	11
1 yr - 2yr	0	0	4	31	6	33	10	22
2yr - 5yr	2	14	5	39	2	11	9	20
3yr - 10yr	0	0	0	0	0	0	0	0
>10yr	4	29	0	0	3	17	7	16
Total	14	100	13	100	18	100	45	100

M: Medics; P: Paramedics; N: Nurses; mth: months; yr: years

Table 4: Participants' job experience since qualification

Job experience since qualification	No. of M	% of M	No. of P	% of P	No. of N	% of N	Total No.	Total %
1st Post	0	0	1	8	7	39	8	18
2nd Post	4	29	2	15	7	39	13	29
Other Posts	10	71	10	77	4	22	27	53
Total	14	100	13	100	18	100	45	100

M: Medics; P: Paramedics; N: Nurses

Table 5: Participants' previous experience of working in other hospitals

Previous experience of work in other hospital	No. of M	% of M	No. of P	% of P	No. of N	% of N	Total No.	Total %
EOH	10	71	9	69	8	44	27	60

EOH: Experience of Working in Other Hospitals
M: Medics; P: Paramedics; N: Nurses

Most of the participants were born in this country with the exception of one nurse, two medics and one paramedic who together represented different ethnic cultures. The majority of nurses were female (n=16, 88%), whilst the majority of medics were male (n=12, 86%) and all the paramedics were female. Generally the medics and paramedics had been educated to first degree level whilst only one nurse had graduated. The majority of nurses had six to nine "O" levels and one to three "A" levels. From the above information it should be possible for the reader to relate the study participants to their own practice situation. The multidisciplinary team was thought to be fairly typical of other such groups working in London teaching hospitals at that time.

DATA COLLECTION

A multi-method approach to data collection was taken and included semi-structured interviews, questionnaires, and participant observation. For ease of explanation the main study can be divided into five different phases of data collection. The tools used in relation to each phase are listed below:

Phase 1: Negotiation

Field Notes

Phase 2: Pre-Innovation

Part 1

Initial Interviews

Patient and Family Participation in Nursing Care Scale (Brooking, 1986)

Part 2

Ward Assessment
- Ward Learning Environment Rating Scale (Fretwell, 1982)
- Nursing Process Measurement Scale (Brooking, 1986)
- Qualpacs Assessment (Wandelt and Ager, 1976)
- Observation for Evidence of LPC

Phase 3: Innovation

Field Notes

Medicine Reminder Card Evaluation

Interviews (SNM- District Nursing)

Phase 4: Post-Innovation

Part 1

Exit Interviews

Part 2

Ward Assessment
- Ward Learning Environment Rating Scale (Fretwell, 1982)
- Nursing Process Measurement Scale (Brooking, 1986)
- Qualpacs Assessment (Wandelt and Ager, 1976)
- Observation for Evidence of LPC

Phase 5: Postscript

Field Notes

In reality, the divisions are not as discrete as the above list suggests. Action research requires flexibility in data collection and the researcher to respond to dynamic changes occurring in reality. During data collection, participants were continually entering and leaving the study as staff changes occurred on the ward (see Appendix IX). However, for the purposes of clarity the data collection is described in its five phases.

Phase 1: Negotiation

The negotiation phase began in February 1988, lasted six months and consisted of fifty two interviews. The Director of Nursing Services gave permission to interview all the Assistant Directors of Nursing Services (n=3), Clinical Nurse Managers (n=7) and Charge Nurses (n=25) of adult surgical or medical wards to ascertain their willingness to participate in the study. I chose to limit my research to these wards rather than specialist departments on account of my own background experience. Thirty five interviews with nursing staff took place during March and April. Interviews were arranged informally by telephone. At interview an outline of the research ideas was given (see Appendix X) and interviewees were asked if they would be interested in the concept of lay participation in care for their patients and if they would be willing to include me as a team member to facilitate change on the ward.

In general the charge nurses were interested in the project ideas and several identified stroke patients as being particularly suited to this approach to care. No ward refused to take part in the study though some wards identified reasons why their participation would not be appropriate. Reasons for not participating included, anticipated staff changes, other research currently being undertaken, no local patients available due to the ward being a regional centre, tendency to take short admissions only, and one ward identified that they were already doing lay participation in care having implemented Orem's Model of Nursing (Orem, 1985).

Out of the twenty wards contacted (some wards had more than one charge nurse), I selected eight wards where the nursing staff appeared particularly interested in developing the research ideas. These wards were revisited and permission obtained from the charge nurses to contact the consultants about the research study. I wanted to take a multidisciplinary approach to innovating change on the ward believing that nurses could not work in isolation when attempting to change patient care. However, even at this early stage of the research project the hierarchical barriers between medics and nurses were encountered. I found medical interviews were more difficult to organise than nurses interviews. Medical secretaries acted as gate keepers and insisted upon having letters before being willing to make appointments although only one written reply was ever received in return! Through sheer persistence I was able to interview fifteen out of sixteen consultants but it took twice as long to arrange these interviews compared with the forty two interviews with other health care staff. Several consultants failed to keep their appointments and eventually one ward was discarded as unsuitable as it was not possible to make contact with one of the consultants despite my attempts to keep several prearranged appointments. At interview I was often conscious of gender and power relations between the participants and myself. This was particularly noticeable when two surgical consultants dismissed the proposed methodology in favour of a controlled clinical trial. They also attempted to persuade me to change the focus of the research to address issues related to their specialities rather lay participation in care. In writing myself into this account it is important to note that it was not normal practice in this hospital for a nurse to be doing research. Even the structure of the application form for ethical clearance reflected a medical dominance which required me to have a consultant's signature before it could be accepted for consideration. On more than one occasion medics questioned the academic status of the proposed research and were surprised to learn that nurses could receive University based undergraduate education let alone register for doctoral studies.

Out of the fifteen consultants interviewed, thirteen were interested in the concept of lay participation in care for their patients and were willing for the study to be carried

out on their wards. There was a tendency for the medical rather than the surgical consultants to welcome the opportunity to change practice. It appeared that they were more in tune with the ideas behind lay participation in care and more conscious of current practice not meeting the needs of patients with chronic illness.

Interviews with the nurses and medics gave rise to suggestions that I should contact various specialists within the hospital to discuss the proposed ideas with them also. These interviews were not planned but the flexible nature of the methodology permitted me to respond to these suggestions. Thus the following specialists were also interviewed:

- 1 Acting Director of Nursing Education
- 3 Occupational Therapists
- 2 Physiotherapists
- 1 Speech Therapist
- 1 Community Liaison Nurse
- 1 Chaplain
- 1 Medical Registrar (research)

The interviews provided a useful opportunity to bounce ideas and gain more insight into which ward would be a suitable for the study. As a result of the interviews, five of the eight wards were discarded as unsuitable for the following reasons:

- consultant refused interview
- consultant did not like proposed methodology
- consultant dominated philosophy of care already in place
- potential role confusion due to researcher being ex-charge nurse on ward

Of the three remaining wards I chose one ward where the consultants had given the most support to the research proposal. I worked on the ward as a nurse for a week to get to know the other team members and ascertain their views on the project. This established a commitment from the multidisciplinary team to do the research. The ward was a general medical ward with a gastrointestinal focus. There was a rich mix of patients from the elderly stroke patient to the young HIV positive patient. The multidisciplinary team described the ward as being in a "rut" and in need of change. They doubted if change would be achieved without the help of a facilitator, as the charge nurse had in the past been reluctant to make changes. When confronted with this issue, the charge nurse said she was not "enthusiastic" for the project to take place on her ward but she recognised the need for change and welcomed the opportunity to have someone

on the team to act as a facilitator for change. She felt lay participation in care would be a useful concept for the patients on her ward and thought she would become more enthusiastic about the research once the project started and was seen to be working. The managers associated with the ward suggested that both the charge nurse and staff nurses might benefit from a researcher's presence which would help to support and facilitate change. It was decided to begin the research on this ward with a view to following up the study on one of the two remaining wards in six months time as a comparative case study. However, due to the slow process of change I remained on the ward of choice for a period of one year and did not attempt a comparative study using the other two wards.

Having negotiated access to a ward with support from both the medics and nurses, ethical clearance was obtained in July (see Appendix XI for proposal presented). The Chairman of the Ethical Committee gave the study a "nod of approval" and was of the opinion that there were no ethical issues to discuss. I had clearly identified in the proposal that ethical issues would be discussed locally with the participants, for example, ownership of sensitive data.

Having undertaken fifty two interviews, I thus carefully and laboriously negotiated access to the selected ward during a period of six months. The importance of the negotiation phase seemed paramount in view of the need for participants in the study to actively collaborate in the research process itself. On reflection I would suggest that important issues in the negotiation phase appeared to be the fact that I was already known by many of the participants and the fact that the flexible research approach did not intend to impose unwelcome ideas on participants. Generally I was made to feel most welcome and felt genuine interest was shown in the project ideas. The study could have taken place on one of several wards.

Phase 2: Pre-innovation

Phase 2 began in September 1988 and focused first on ascertaining views on lay participation in care with the purpose of developing a ward policy and second, on assessing the ward to establish a baseline, against which to measure change.

Part 1: Views on lay participation in care

Views on lay participation in care were gathered from health professionals through semi-structured interviews and the completion of an attitude scale (Brooking, 1986).

Initial Interviews

The semi-structured interviews began in September and included all qualified members of the multidisciplinary team on the ward chosen for the study. The purpose of these interview was two fold. First, it was used to gather data on the health professionals perceptions of lay participation in care and second, to ascertain what changes the team wanted to make on the ward to facilitate lay participation in care. Participants commented frequently that they had not really thought about lay participation in care and found the interview thought provoking. For this reason all new members of staff entering the ward during the research study were similarly interviewed. The interviews also served to establish a working relationship between the participants and myself in that after the interview we often talked at length about our various roles on the ward. Interviews were taped and later transcribed verbatim. During the study a total of forty five initial interviews occurred with a variety of members of the multidisciplinary team (see Table 1).

The interviews lasted between forty minutes to one and a half hours and were guided using a schedule of open ended questions (see Appendix XII). Questions invited participants to share their understandings of lay participation in care and make suggestions as to how practice might be changed to lay participation in care in practice. Where possible the interviews took place outside the environment of the ward to reduce the risk of interruption. I tried to informally arrange interviews within the participants' work time. It meant that considerable time was spent waiting for the ward to be relatively quiet so that a member of staff could be released for interview. This had some benefits in as much as I had time to establish relationships with the participants before the interview. Thus generally they were at ease being tape recorded as they were already used to having conversations with me. Moreover on the ward I quickly became identified as a person who had time to listen and so prior to the interview many participants had already shared with me their problems and concerns connected with their work and personal lives. The interviews were also helped by the fact that I had considerable knowledge and experience of interviewing skills.

Participants were assured of confidentiality and anonymity. It was made clear at the interview that anything that they did not feel comfortable about would not be published. Transcripts of the interviews were given back to the participants for checking and alteration. Apart from a general concern that participants wished they had been more articulate, no participant requested that their transcripts be altered. However, one nurse chose not to be tape recorded but was given the field notes to read. She did ask for an alteration to be made to her interview because she felt she had come across as feeling

very negative towards nursing. We discussed whether this was because I had portrayed her inappropriately in the field notes or whether she had been having an "off day". We agreed it was important to change her comments if this did not really represent how she felt usually.

Patient and Family Participation in Care Scale

The Patient and Family Participation in Nursing Care Scale Brooking (1986) was used to ascertain the health professionals' attitudes towards lay participation in care. This scale supplemented and triangulated with the data obtained at interview, required participants to focus on specific aspects of lay participation in care which they may not have considered without the stimulus of the questionnaire. The questionnaires alone would not have been sufficient to ascertain the health professionals' perceptions of lay participation in care. In early pilot work Brooking (1986) had found that abstract concepts of patient and family participation in care were unfamiliar to the health professionals. She discovered that simply asking her subjects for general opinions produced meaningless results. This led her to design a highly structured questionnaire but during her study the limitations of survey methods generally became apparent. She concluded that additional observations and semi-structured interviews would have been a useful adjunct to the questionnaires and might have provided richer, more meaningful data. Therefore the present study set out to use all these approaches to ascertain the health professionals' perceptions of lay participation in care.

The Patient and Family Participation in Nursing Care Scale is a self completion questionnaire designed to examine current practices, opinions and attitudes towards patient and family participation in nursing care (see Appendix XIII). For health professionals it consists of the following different sections:

Section 1 - Attitudes Towards Patient and Family Participation in Nursing Scale *
consisting of: Patient Planning Subscale
Patient Implementation Subscale
Relative Planning Subscale
Relative Implementation Subscale

Section 2 - Care Activities in Hospital Scale *

Section 3 - Nurses' Organisation of Care Scale

Section 4 - Official Policies Towards Nursing Issues

Section 5 - Nurses' Attitudes Towards the Nursing Process Scale

Section 6 - Suggestions for Change

Section 7 - Other Comments

**The nurses in the study were given the entire questionnaire to complete but the other multidisciplinary team members (medics and paramedics) were given those parts that did not require a specific nursing knowledge. Thus sections relating to the organisation of nursing care, nursing process and nursing policies were omitted for non-nurses.*

In some ways this particular data collection had an educational purpose. The interviews revealed that participants had often not really thought about lay participation in care and by asking them to complete a questionnaire it encouraged them to think about the concept before trying to plan ways of putting it into practice. An additional page was added to all the questionnaires inviting again suggestions of changes that might be made on the ward to facilitate lay participation in care (section 6) and asking for any other comments on the subject (section 7).

A further modification to the questionnaire was made so that participants had to give an opinion. Brooking (1986) had found that acquiescence and "response set bias" to be a problem with the questionnaire. Respondents often ticked the "Don't know" category or gave "middle of the road" answers. The "Don't know" option was therefore deleted and the Likert scale of five categories thus reduced to four categories. This modified version of the attitude scale was given to all multidisciplinary team members at the beginning of the study or as they joined the ward. Participants were asked to complete the questionnaire in their own time. They were given it after their initial interview in order that it would not influence what was said during the interview. The questionnaire was also given to those nurse learners who were allocated to the ward for more than four weeks and who were not on their first ward allocation (first warders). This was done more for an educational exercise for the learners themselves as they were not being interviewed on account of their transient role. It was considered more important initially to concentrate on the views of the permanent trained staff as they would be responsible for ensuring any future changes on the ward. However, all the learners were given a teaching session on lay participation in care early in their allocation so that they could be informed of the ward's changing philosophy. It did not seem appropriate to give the questionnaire to learners who were on the ward for less than four weeks, nor during their first allocation, as some of the questions invited them to make comment on the ward practice as regards lay participation in care. Thus in total the modified version of the Patient and Family Participation in Care Scale was completed by fourteen qualified nurses (response rate 78%), seventeen learner nurses (response rate 81%), eleven medics (response rate 79%) and nine paramedics (response rate 69%). A total of sixty six questionnaires were distributed, of which fifty one were returned, giving a overall response rate of 77%.

Part 2: Initial ward assessment

The second part of Phase 2 focused on assessing the ward so that a comparison could be made to determine if innovation had changed practice in any way. A multi-method approach was taken consisting of collecting data on the following factors:

- Ward Learning Environment Rating Scale
- Nursing Process Measurement Scale
- Qualpacs Measurements
- Observation for Evidence of Lay Participation in Care

Ward Learning Environment Rating Scale

Ward Learning Environment Rating Scale (Fretwell, 1982), was used to assess the ward learning environment (see Appendix XIV). The questionnaire was designed to rank wards into "good" and "less good" from a teaching and learning point of view. It followed a design used by Bendall (1973) and sought opinions on the following areas:

- what there was to learn
- what nurses felt they had learnt
- whether they felt all learners would benefit from working on the ward
- teaching by the ward sister, consultant and clinical teacher
- supervision of new procedures
- how the ward compared with other wards
-whether they liked working on the ward.

The tool consists of nine sets of statements concerned with nurse training in the ward situation. The learner is expected to ring one statement closest to his or her own view for each of the sets of statements. The statements are worded in such a way that it is possible to identify a "good" ward learning environment. In the present study it was used to ascertain if there were any perceived differences over time in the quality of the ward learning environment of the ward under study. The questionnaire was modified slightly to include a few questions at the end so as to encourage a more open ended response. In this respect learners were asked to comment on how they felt about working on the ward, how they felt about the patient care on the ward and whether they saw patient care on the ward to be any different to other wards.

At the beginning of the project the ward under study was not thought to have a good ward learning environment since concern had been expressed by the school of nursing about its suitability for learners. Moreover some participants had indicated the

same at interview. This was therefore thought to be one area which was likely to change during the period of the study and which could be measured. Given that the study was concerned with introducing lay participation in care and which entailed health professionals changing their roles from "doer" to "educator and supporter", measuring the ward learning environment seemed an appropriate indicator of change. In order to offer lay participation in care, the health professionals needed to ensure that the staff coming into contact with the patients were well informed. Attention needed to be paid to the learners' understanding of patient needs and ward practice. To facilitate such learning, as well as the education of patients, an improvement in the ward learning environment was essential. I decided to monitor the ward learning environment throughout the project so that changes could be monitored over time. All learners who were staying on the ward for more than four weeks and who were not first warders were asked to complete the "Ward Learning Environment Rating Scale" (Fretwell, 1982). They were selected because the project required them to have worked on the ward for a period of time (four weeks) before being able to comment on ward practice and also to have worked on other wards to be able to make the ward comparisons asked for in the questionnaire. This questionnaire was designed for use with learners only and so was not given to other participants. The transient nature of their work meant that they frequently changed wards (usually every eight to ten weeks) and were therefore best placed to assess the differences between wards as a learning environment. A total of twenty one questionnaires were given out and eighteen were returned thus representing a response rate of 86%.

Nursing Process Measurement Scale

Another aspect of the ward practice likely to be influenced by the introduction of lay participation in care was the use of the "nursing process" on the ward. The nursing process is a systematic problem solving approach to nursing care that places the patient at the centre of planning and evaluating care (De La Cuesta, 1983). It has been argued that participation of the patient in the nursing process is imperative on account of their non-compliance with therapeutic objectives set by nurses (Steckel et al., 1979). Given that patients frequently need to integrate new behaviours and significantly modify their lifestyles to promote health, prevent illness and adapt to continuing disability, their participation in the nursing process is thought to be essential (Conway-Rutkowski, 1982). Once again the ward used for the study did not have a good reputation within the hospital for using the nursing process and it was thought that when lay participation in care was introduced it would influence the way in which care was being delivered. Thus it was predicted that a higher score for the nursing process would be achieved. It was perceived as another way of monitoring the effect of introducing lay participation in care on the ward.

Brooking (1986) developed a scale to measure the extent to which the nursing process was being used in hospital wards. The scale consists of three components, "Ward Nurses' Self-rating Scale", a "Ward Observation Schedule" and a "Senior Nurses' Ward Rating Scale". However, Brooking suggests that any one or two of the three components (Senior Nurses' Ward Rating Scale would produce the weakest data) could be used to obtain an estimate of the use of the nursing process. In the present study the Ward Nurses' Self Rating Scale was used on its own (see Appendix XV). It consists of thirty seven items and can be divided into a section for general points (four items), plus four subscales including, Subscale for Assessment (eight items), Subscale for Planning (nine items), Subscale for Implementation (ten items) and Subscale for Evaluation (six items). Subjects are expected to respond to each item by ticking one of six boxes and are awarded scores as follows:

- yes, always/excellent (score 6)
- yes, usually/good (score 5)
- yes, often/fair (score 4)
- sometimes/poor (score 3)
- don't know (score 2)
- no, never (score 1)

Thus each item is scored from 1 to 6 with a 0 score for blanks. This produces a cumulative score from 0 to 222.

This self-rating questionnaire was designed for use by qualified and learner nurses. A total of thirty nine questionnaires (18 qualified and 21 learners) were distributed and thirty two (14 qualified and 18 learners) returned, representing a response rate of 82%. As with the Ward Learning Environment Rating Scale, the data from the questionnaire were gathered over time as qualified nurses joined the ward staff and as learners were allocated to the ward for a period of longer than four weeks.

Qualpacs Measurements

Because lay participation in care is concerned with an approach to care that attempts to individualise care and break down barriers between lay people and health professionals, another way of determining if any change has occurred as a result of the project would be to examine the quality of care. Qualpacs (Wandelt and Ager, 1976) were used to measure the quality of care given on the ward and nurse researchers working in the hospital made the Qualpacs assessments both at the beginning and end of the study.

The Qualpacs is a sixty eight item scale for measuring the quality of care received by patients either from direct nurse-patient interactions or from interventions on behalf of the patient. The scale is concerned with six areas of care:

- care received directed toward meeting psycho-social needs of the patient as an individual
- care received reflecting recognition of the patient's psycho-social needs as a member of a group
- care received meeting physical needs
- care received meeting both psycho-social and physical needs at once
- dealing with communication
- dealing with professional responsibility

The Qualpacs assessment involves five or six patients randomly selected to represent the quality of care received by patients on the ward. Patient care is directly observed using a rating scale to guide the observations. The rating scale allows for a possible range of scores : best (score 5), between (score 4), average care (score 3), between (score 2), and poorest care (score 1). The expected norm is "best care" for one or all the patients (Wandelt and Ager, 1976).

Observation for evidence of lay participation in care

Observation of lay participation in care was on-going throughout the study. Data were gathered by participant observation methods and recorded in daily field notes. However, at the beginning and end of the study particular attention was paid to observing ward reports and ward meetings to identify evidence of lay participation in care.

Observation of ward reports I attended lunch time ward reports (five days per week) for one month at the beginning and end of the study. Notes were taken on the patients discussed, in particular recording whenever patients or their relatives and friends were mentioned to be participating in care. In this respect participation in care was considered at two levels: participation in decision making and participation in practical care.

Observation of ward meetings Multidisciplinary team meetings were held once a week to discuss lay participation in care and plan care for the following week. I attended these meetings for one month at the beginning and end of the study, making notes of patient, relative and friend participation in care. Again, I focused on participation in decision making and practical care.

Thus Phase 2 began in September and was divided into two parts. The first part focused on ascertaining views on lay participation in care with the purpose of developing a ward policy. The second part focused on assessing the ward for a variety of factors for comparison at a later stage with a view to establishing if change had occurred. Whilst much of the data collection was on-going throughout the study as new staff arrived on the ward and needed to be interviewed and/or given questionnaires, sufficient data had been gathered by the end of October to begin the process of feedback to the ward as part of Phase 3.

Phase 3: Innovation period

During the period of the innovation I worked every day on the ward as a participant observer and facilitator of changing practice. Schatzman and Strauss (1973) discuss the concept of watching as an "active presence". They describe six different types of observation depending on the extent to which the researcher interacts with the participants: "watching from outside"; "passive presence"; "limited interaction"; "active control"; "observer as participant" and "participation with hidden identity". Observer as participant best describes the role taken by me in the present study. In the study I was a full participant in the on-going activities whilst simultaneously my identity as a researcher was known. Schatzman and Strauss (1973) identify several disadvantages of full participation as researcher which stem from the demanding qualities of the participation itself. First, if the participatory activities are especially demanding of energy and time the research work suffers. Second, the foci and range of attention is largely directed by the participatory work and can thereby be limited. Third, not all participatory work yields valuable research data. Finally the researcher is more at risk of going "native" where by she becomes "over involved" with one particular perspective due to the intense engagement, and other viewpoints therefore remain unchallenged. Whilst I was exposed to all these concerns, I would argue that working as an "observer as participant" is somewhat different in action research. In action research the participant's role is to act as an insider and be part of the team to facilitate and monitor change. This means that whilst the researcher role is not obtrusive, it is still a recognised part of one's every day work. Thus participation does not really involve a distraction from the research activity but is the focus of the research. "Going native" is also less problematic as feedback to the participants ensures that all view points are represented and thus there is less risk of becoming over involved with any one perspective. Furthermore writing the research as a self-reflective enquiry ensures that issues, such as the risk of "going native", are addressed publicly. On the other hand the advantages of being an "observer as participant" as identified by Schatzman and Strauss (1973) hold true for action research. They argue that full participation allows accessibility to certain situations and information not normally made accessible to the outside researcher. It is my belief that by being a co-

worker and friend participants confide and share more of the reality of their experiences. Furthermore by participating within the organisation the researcher gains valuable insight into what it feels like to work in that environment. These experiences describing the process of doing the research and monitoring the innovation were recorded in daily field notes. The findings were fed back to the team throughout the data collection. At the end of the study the field notes were analysed more systematically.

Innovation - medicine reminder card evaluation

During the study, the medics identified a concern of non-compliance in drug taking amongst patients. As part of the project they wished to evaluate the use and effectiveness of giving patients medicine reminder cards (Appendix VI). House officers were asked to issue patients with the cards and educate them about their treatments. Patients would be asked to continue monitoring their drug taking at home and report back in the outpatients department on the usefulness of the cards. Instructions for their use were given to the house officers and an evaluation form was adhered to the patients notes to be completed by the medics on the patient's return to the clinic (Appendix VII). It was my role to monitor the process of this evaluation, reporting back at the weekly meetings over a period of seven months. I kept a record of all those patients who should have been given a medicine reminder card and monitored those who were actually given them. Evaluation forms from the outpatients clinic were returned to me for analysis. The results of this aspect of the project are reported in full in the findings chapter. Suffice it to say the reports were extremely disappointing and highlighted other important issues concerning the difficulties in changing practice. Such issues were recorded in the daily field notes and serve to illustrate the importance of monitoring the process of change as well as outcome.

Interviews - senior nurse managers (district nursing)

During the innovation it was suggested that the Senior Nurse Managers (District Nursing) might be interested to learn of the project as patients would be discharged into the community and would require their follow-up. Once more the flexible nature of the research approach meant the meetings could be used as part of the data collection. I therefore sought permission to make notes on their comments and wrote these up as detailed field notes after the meetings. A total of eight Senior Nurse Managers (District Nursing) were interviewed. All found the topic directly relevant to their work and contributed some interesting comments. These qualitative interviews were totally unstructured and lasted anything from twenty minutes to two hours.

Informal conversations in the field

Other meetings occurred spontaneously during data collection and were either tape recorded or written as field notes. For example, contextual information, such as, the changes in the ward's reputation within the hospital, was given by the Assistant Director of Nursing Services, Clinical Manager and Senior Tutor associated with the ward. I endeavoured to remain open and responsive in my data collection throughout the innovation. The openness and willingness to listen in order to understand what was happening from many varying perspectives added richness to the data collection. It also established a relationship of trust between the participants and myself whilst frequently reporting back findings for participants to consider what action to take next. This did however raise some important ethical issues which are reported in a later section of this chapter.

Phase 4: Post-innovation

Phase 4 began in July 1989 and falls into two parts in terms of data collection. The first part is concerned with interviewing participants about how they perceived the project had developed and the second part repeats some of the ward assessment data collection to ascertain if change had occurred on the ward as a result of attempting to introduce lay participation in care.

Part 1: Exit interviews

Team members left the ward at regular intervals throughout the data collection. It was decided six months into the study, to interview all those multidisciplinary team members who were leaving the ward. Interviews were not undertaken prior to this time as the project had not been sufficiently established to warrant close scrutiny. Because by then some attempts at change had been made, it seemed appropriate to give participants a formal opportunity to reflect on what change (if any) had taken place and how they felt about it.

Many months into the project, the charge nurse resigned her position and a new charge nurse was appointed from within the hospital, who specifically requested to come to the ward to be involved with the research. This created a natural break in the project and it was decided to round off the data collection by interviewing all the multidisciplinary team members still working on the ward to establish their views on what had (or had not) happened on the ward in terms of change.

A total of twenty five final interviews took place which included eight nurses, ten medics and seven paramedics. No one refused to be interviewed although two requested

not to be tape recorded. In these instances notes were taken during the interview and were written up in full later. At interview a semi-structured interview was used to explore the participants' experience of the project (see Appendix XVI). Participants were again asked to define lay participation in care to once more ascertain their understanding and perceptions of the concept. Next they were asked to reflect on what changes had occurred on the ward as a result of the project and to comment on why things had occurred in the way that they had. Finally they were asked to consider the desired changes that had not occurred and explore the possible reasons. The interviews whilst guided by a semi-structured schedule tended to evolve in different ways depending on what the participant wanted to talk about in relation to the project. Thus they varied in length between thirty minutes and two hours.

Part 2: Exit ward assessment

The same framework used in Phase 2 was used in Phase 4 to assess the ward for any changes during the course of the innovation. They were:

- Ward Learning Environment Rating Scale
- Nursing Process Measurement Scale
- Qualpacs Measurements
- Observation for Evidence of Lay Participation in Care

NB The use of Ward Learning Environment Scale and Nursing Process Measurement Scales had been on-going throughout Phase 3.

This period of data collection lasted for one month from May to June, during which the original charge nurse left and an acting one appointed before the arrival of the new charge nurse in July. This was a difficult period for the research study. Whilst it produced a commitment from the hospital to be responsible for the continuation of the project even after my withdrawal as a researcher (see Chapter 1), it was very difficult to develop further any project ideas in the absence of a permanent leader. During this time I saw my role as keeping the project in the minds of the multidisciplinary team in preparation for the new charge nurse's commencement of duty on the ward.

The arrival of the new charge nurse required me to re-negotiate my role and presence on the ward. Data collection for the doctoral study was near completion but I still felt a deep commitment to assisting the continuation of the project under the new leadership. It was agreed that I would give one day per week to offer support and advice to the new charge nurse in her role as change agent. Data would continue to be gathered in the form of field notes and the project moved into Phase 5.

Phase 5: Postscript

Phase 5 began in August and contact continued with the ward until June. The contact took the form of regular support meetings, to discuss the project, with the new charge nurse. The meetings were recorded in field notes and constituted the postscript data. Many of these data confirmed numerous issues highlighted in earlier phases of the research and has been an important part of the data collection in validating findings. They were analysed in the same manner as the other field notes for issues and problems concerning health professionals' perceptions of lay participation in care and the difficulties of changing practice.

During this phase the new charge nurse carried out some independent evaluation of the multidisciplinary team practice funded by regional research moneys. Later she was awarded a grant by the Department of Health to register for a PhD to examine the lay perceptions of lay participation in care. This marked the end of the data collection as there was a need to pass on the responsibility of the project to the participants and for it to continue to develop independently.

The following section addresses the methods used to analyse the various sets of data collected.

METHODS OF DATA ANALYSIS

As with the data collection, an eclectic and pragmatic approach was taken when analysing the data. Whilst it was appreciated that the data were to be presented to other health professionals, who in the main held positivist notions of science, it seemed appropriate to mix quantitative and qualitative methods, even though it is recognised that such an approach is contentious (Brewer and Hunter, 1989). Mixing quantitative and qualitative methods of data analysis also facilitated comparison of results between groups.

The mixing of quantitative and qualitative approaches in the analysis of findings is supported by Miles and Huberman (1984). Their stance is that social phenomena exist not only in the abstract but also in the objective world. They argue that phenomena exist objectively in the world because people construe them in common or agreed-upon ways, so these perceptions are crucial in understanding why social behaviour takes the form that it does. For Miles and Huberman the task in qualitative data analysis is to express these social regularities as precisely as possible, attending to their range and generality and to the local and historical contingencies under which they occur. They place considerable emphasis on the importance of evolving a set of valid and verifiable methods for

capturing these social relationships in order that others using the same tools will arrive at analogous conclusions. Whilst inclining clearly towards a more inductive methodology for illuminating social processes, they take issue with the somewhat magical approach to the analysis of data used by some ethnographers and social phenomenologists who do not communicate their methods of analysis on the grounds of it being idiosyncratic, incommunicable and artistic. Instead, Miles and Huberman are committed to clarity in qualitative analytic procedures requiring the researcher to be explicit about the structure of the analysis itself. They suggest that the analysis of qualitative data consists of three concurrent flows of activity: data reduction, data display and conclusion drawing and verification. Data reduction consists of the process of selecting, focusing, simplifying, abstracting, and transforming the "raw" data. Data display is defined as an organised assembly of information that permits conclusion drawing and action taking. They suggest that the most important form of display for qualitative data in the past has been narrative text which they argue is dispersed, sequential rather than simultaneous, poorly structured, and extremely bulky. Data displays can consist of matrices, graphs, networks, and charts. The final form of analysis activity as described by Miles and Huberman is that of conclusion drawing and verification. They suggest that this activity is on-going throughout any study as the researcher begins to decide what things mean, note regularities, patterns, explanations, possible configurations, causal flows, and propositions (Miles and Huberman, 1984). In the present study data were systematically analysed and reduced to tables which can be viewed in the appendices. The tables display all issues raised by participants and show how the issues raised were grouped into themes. They also indicate how many participants in each group subscribed to each theme. Thus presenting all the raw data in this way the reader should be able to judge better the validity of the findings and assess my interpretation of events. However, a decision was taken to describe only the main themes in narrative form in the main body of the study. This was done to preserve the quality of the findings and was thought to be a better way of communicating to the reader the detail and depth of what had happened during the action research study . In this way all findings are presented and it is hoped that the enumeration of themes will be perceived as an additional dimension rather than a detraction from the qualitative nature of the findings.

Miles and Huberman's approach to data analysis was considered especially suited to the present study. I believed that unless I was truly explicit about the analysis, given that I was working in such close relationship with the participants, I might be vulnerable to the research being disregarded as subjective and anecdotal. Whilst I do not personally share the same concerns as Miles and Huberman in respect of the mystical nature of qualitative analysis, I recognise that this might be because of my own socialisation and apprenticeship in its practice. However, the multidisciplinary audience for whom I am

writing might not be so familiar and so a more structured approach seems more appropriate. In action research the audience should always be considered since the very essence of the work is to influence practice (Somekh, 1994). I had no worries about the multidisciplinary team accepting the findings because it is they who owned them. The validation of the findings rested in part on their acceptance of them. If disagreement occurred over the acceptance of the findings this was written into the report. However, my concern is really with the wider audience of health professionals who will read the study and need to be in a position to judge its relevance for themselves.

Thus it can be seen that an eclectic and pragmatic approach to data analysis was taken which mixed qualitative and quantitative methods. The section below describes in more detail the analyses used for each method of data collection.

Analysis of initial interviews

Interviews were transcribed verbatim and checked with participants for accuracy of understanding and for possible changes. Transcripts were read repeatedly and notes made in a margin at the side of the issues being raised by participants in relation to the questions being asked at interview. Data that emerged unrelated to a question were similarly noted. For instance, no direct question was asked in relation to the state of the ward. However, at initial interview when participants were asked if they thought the ward was ready to change, they freely commented on how they perceived the state of the ward to be in relation to potential change and so this became a section in its own right. Next, under the headings of questions asked or under the headings of sections that naturally emerged from the data, each of the issues in the margin were transferred onto a large matrix which detailed which participant had made which comment. Following this the data were transferred to a matrix on the computer using a word processing package. This displayed the data in terms of how many people in each group (medic, paramedic, nurse) had raised each issue and also grouped issues into themes. This systematic approach to data analysis and display meant that at any one time it was possible to track specific individuals who had raised particular issues. This made it easy to go back to the original transcripts to check for meaning and locate suitable quotes to illustrate points being discussed. Whilst the process was extremely time consuming it allowed the quality of the data to remain intact but at the same time added a quantitative dimension which allowed for easy comparison between groups (see Appendix XVII for an example of the analysis process used).

Analysis of patient and family participation in nursing care scale

The data from the Patient and Family Participation in Nursing Care Scale were analysed using non-parametric techniques of hypothesis testing in the statistical software

package SPSS-X (SPSS Inc, 1988). Basic descriptive statistics were used to summarise the data from both the nurses' questionnaire and the non-nurses' questionnaire. Frequency distributions were then performed to look at the spread of the data. Cross tabs and Chi-square were used as an exploratory data analysis to display the data. Since the significant difference in cross tabs could have been caused by many small cells and since the data were not sufficient in quantity, the Mann Whitney and Kruskal-Wallis tests (Siegal and Castellan, 1988) were used to analyse the variance between groups.

The Mann-Whitney test was used to determine any significant difference between the qualified and learner nurses' data. This is a non-parametric test for two independent samples, and is the non-parametric equivalent of the two sample independent t-test. It is best used on data where the assumptions for the t-test are not met, or where the level of measurement is weaker than interval level. It does not require normality, or even approximate normality but assumes random samples (unless samples are not biased), independent samples and independence within each sample.

Whilst the Mann-Whitney test looks at two groups the Kruskal-Wallis test looks at more than two groups. The data sets were thus joined and the Kruskal-Wallis test used to compare the qualified nurses, learner nurses, medics and paramedics. The Kruskal-Wallis test is a generalised form of the Mann-Whitney and has the same requirements and assumptions.

The data from this questionnaire were also useful to gauge whether this small group of health professionals held different views about patient and family participation in care from the larger group of health professionals who were surveyed as part of Brooking's (1986) study. This information was thought to be valuable since it might help the reader to be in a better position to judge whether the health professionals in the present study were typical or atypical. Data from the "Care Activities in Hospital Scale" and the "Patient and Family Participation in Nursing Care Scale" were therefore compared with the same data from Brooking's study. However, a direct comparison was not possible since Brooking's scale had been modified to take out the "don't know" category in order to force a positive or negative response. Instead the trends towards giving more negative or positive scores was examined. The following points were awarded for each change in percentage shift.

Awarded	+1	if positive shift	<10%
	+2		11-20%
	+3		21-30%
	+4		31-40%
	+5		41-50%
	+6		51-60%
Awarded	-1	if negative shift	<10%
	-2		11-20%
	-3		21-30%
	-4		31-40%
	-5		41-50%
	-6		51-60%

Analysis of Ward Learning Environment Rating Scale

The data from Ward Learning Environment Rating Scale were analysed using the statistical software package SPSS-X and non parametric hypothesis tests were used. Basic descriptive statistics were used to summarise the data and frequency distributions were then performed to look at the spread of the data. Scatter plots were used to look at each question over time. Each question was then correlated with the each of the other questions using the Spearman rank correlation coefficient (Siegal and Castellan 1988). The Spearman rank correlation coefficient measures the degree of linear association between the ranks of two variables. The closer the population Spearman rank correlation coefficient is to -1 or 1, the stronger the linear component of the relationship between ranks of the variables. If the population Spearman rank correlation coefficient is 0, the ranks of the variables can still be strongly related in a non-linear way. The Spearman rank correlation coefficient was used in preference to the Pearson correlation coefficient on account of the non normal distribution. The Spearman rank correlation coefficient requires a random sample of subjects (unless the sample is not biased), paired samples and independent observations within each sample. Following this each question was correlated against time using once again the Spearman rank correlation coefficient.

Analysis of the nursing process measurement scale

The data from the Nursing Process Measurement Scale were analysed using the statistical software package SPSS-X and non parametric hypothesis tests were used. As with the analysis of the Ward Learning Environment Rating Scale, basic descriptive statistics were used to summarise the data and frequency distributions were then performed to look at the spread of the data. Scatter plots were used to look at each item over time. Each item was then correlated with each of the other items using the

Spearman rank correlation coefficient. Once more the Spearman rank correlation coefficient was used in preference to the Pearson correlation coefficient (Siegal and Castellan, 1988) on account of the non normal distribution. Following this each item was correlated with time using the Spearman rank correlation coefficient. The data set was then split into qualified and learner nurses and each item for each group was correlated with time. In this way it was possible to see if there were any differences in responses between the qualified and learner nurses, which may or may not have affected the overall findings and ascertain if the ward was improving with regard to the nursing process during the course of the study.

Analysis of field notes

Throughout the study daily field notes were recorded. The field notes were systematically analysed for issues relevant to the professionals' perceptions of lay participation in care, the change process itself and on the process of doing the research. Initially these issues were noted in the margin of the eight hundred and thirty four pages of hand written field notes (A4 size). On account of being an active participant in an action research study which had encountered many stressful events, it was felt necessary to take into account the process of doing the research. For this reason the analysis of the field notes began by examining the feelings experienced by me during the study. A note was made of the month, page number (for ease of cross reference) and whether the issue raised was seen as inducing "positive", "interesting" or "negative" feelings in me. In this way issues could be systematically traced back to their original source for confirmation and the feelings engendered in the process of doing the research explored over time. These issues and problems were then analysed for each month and grouped under themes. It was possible therefore to examine the emergence of feelings and themes over time. These data concerned with the process of doing the research are addressed in more detail in the self reflective enquiry chapter (Chapter 8). Having traced the engendered feelings in the research process, the significant events which occurred during the study were highlighted and these data formed the basis of the story told in the first chapter of the thesis (Chapter 1). Finally the issues raised (positive, negative and interesting) were grouped together and analysed for emerging themes. These themes are described below.

Within action research smaller projects often emerge as a result of practitioners asking questions about their practice (McNiff, 1988). The researcher works in response to suggestions made by the participants as part of the project. In the study most of suggestions for change were evaluated by previously mentioned tools; in particular the interviews and participant observation field notes. However, two other aspects of data collection emerged as a result of suggestions from the participants during the course of the study. This included the evaluation of the medicine reminder card system to improve

patient drug education and the interviewing of senior nurse managers (district nursing) to gain an understanding of the community professional's perspective of lay participation in care. Finally data were collected on an informal basis as participants in the field had something relevant to say about the research. On occasion such conversations were recorded as field notes whilst at other times they were tape recorded and transcribed. The transcripts were analysed as complementary data to the field notes and are not therefore presented as separate findings in the study.

Thus a variety of methods were used to analyse the data. These methods mixed qualitative and quantitative approaches in such a way that they added richness to the findings and facilitated easier comparison between groups. Essentially an eclectic and pragmatic approach to data analysis was used. In so doing findings can perhaps be understood and accepted more easily by those participants who are more familiar with positivist approaches to research. Furthermore the systematic approach to data analysis ensures that the development of themes can be tracked and validated and individual transcripts identified for relevant illustrative quotes.

ISSUES OF RELIABILITY AND VALIDITY

All scientific research strives to demonstrate authenticity of results, often through discussions concerned with validity and reliability. The present study took an eclectic approach to data collection and used both quantitative and qualitative methods. Issues of reliability and validity will therefore be addressed under these subheadings.

Quantitative Data

In quantitative research, validity refers to the degree to which an instrument measures what it is supposed to be measuring and reliability is the degree of consistency with which an instrument measures the attribute it is supposed to be measuring (Polit and Hungler, 1985). In the present study quantitative measures were used to assess the health professionals' perceptions of lay participation in care (Patient and Family Participation in Nursing Care Scale - Brooking, 1986) and to determine whether change took place on the ward over time (Ward Learning Environment Rating Scale - Fretwell, 1982; Nursing Process Measurement Scale - Brooking, 1986 and Qualpacs Assessment - Wandelt and Ager, 1976). The limitations of using structured instruments to measure complex phenomena are demonstrated in this thesis. The quantitative tools were not chosen for their proven validity and reliability but rather for pragmatic reasons. In the cultural setting, participants were more familiar with quantitative methods of data collection and were naturally inclined to use such measures to monitor change. Furthermore some of the tools used had been developed within or were in common use in the hospital setting.

The importance of using culturally sensitive methods in action research has been explored before (Somekh, 1994).

Since the present study was completed, Norman (1994) has shown that the Qualpacs measure is the most valid of the three generic instruments commonly used in practice to measure the quality of nursing care (Monitor - Goldstone et al, 1983; Senior Monitor - Goldstone & Maselino-Okai, 1986 and Qualpacs - Wandelt and Ager, 1976). However the other measures used in the present study (Ward Learning Environment Rating Scale; Nursing Process Measurement Scale and Patient and Family Participation in Nursing Care Scale) cannot claim such rigorous testing. Whilst both the Patient and Family Participation in Nursing Care Scale and the Nursing Process Measurement Scale are asserted to have face and content validity plus reasonable levels of reliability, neither have been examined for construct validity (Brooking, 1986). Similarly, whilst the Ward Learning Environment Rating Scale has been subsequently developed and further tested (Fretwell, 1985), the version used in the present study can only claim face and content validity. It followed a design by Bendall (1973) and, although shown to reliably distinguish between "good" and "less good" wards (from a teaching/learning point of view), was never claimed to be anything other than a crude measure of opinion (Fretwell, 1982).

From the above it should be noted that, whilst the quantitative tools used in the present study might claim reasonable levels of reliability, they were limited to a greater or lesser degree in terms of their validity.

Qualitative Data

Some researchers would argue that the unequivocal determination of the validity and reliability of findings in qualitative research is not really possible (Becker, 1958; Lofland, 1971). For phenomenologists there is no social reality to be accounted for as every situation is perceived and determined by the individual social actors involved and therefore they would argue that issues of validity and reliability are misconceptions. However others would argue that because qualitative research often relies on "artistic" and "intuitive" approaches to analysis, the plausibility of qualitatively derived findings are in serious doubt (LeCompte and Goetz, 1983). These people would advocate the need to address threats to credibility using a different set of techniques to those used in more quantitative research (Duffy, 1985) and would suggest that to ignore these threats weakens the results of the research (Miles and Huberman, 1984).

Guba and Lincoln (1981) argue that the techniques required in new paradigm research to give confidence in the trustworthiness of data are triangulation, reflexivity and member checks. The present study uses all three techniques and the following section describes each in turn.

Triangulation

According to Lather (1986) triangulation is critical in establishing trustworthy data and includes multiple data sources, methods and theoretical schemes. He stresses the need for the research design to seek counter patterns as well as convergence. By triangulating the data through a multi-method approach the distortions from a single data set and possible researcher bias are thought to be minimised. Redfern and Norman (1994) explore the limitations, strengths and challenges of triangulation and suggest that despite its complexity, it is a valuable approach for investigating social phenomena. In the current study a variety of methods of data collection are used (qualitative and quantitative) to assess the health professionals' perceptions of lay participation in care. In this way it is possible to examine inconsistencies in the data and make comment on what health professionals say in theory about lay participation in care and what they actually do when confronted with implementing the concept in practice. It is argued that data generated from action research is more trustworthy because it deals with issues in the reality of everyday practice.

Action research also acknowledges the role of history in influencing findings and seeks to describe the setting in its historical context. For instance, in the study, account has been taken of the historical and socio-political influences in terms of the health professionals understanding of lay participation in care and also of the wider influences on changing practice. It is argued that, by looking at the data from a variety of perspectives, the trustworthiness of the findings is maintained. Furthermore, by using a variety of methods (including participant observation), it is suggested that the action researcher is better placed to share common understandings of practice with participants and that this also contributes to the findings being more valid.

Reflexivity

Guba and Lincoln (1981) argue the need for reflexive subjectivity in substantiating the trustworthiness of data in new paradigm research. In the present study, by writing myself into the account, I hope to acknowledge possible influences in an attempt to be free from bias. Within action research there is a clear need to qualify the investigator's social role within the research site as this will clearly effect the flow of information. It is argued that, by writing action research as a self reflective inquiry, attempts are made to guard against the unusual effects of being a long term observer such

as contrivance, going native, research exhaustion, ethnocentrism and perceptual bias. Furthermore, writing oneself into the account is essential if one is to facilitate others to repeat the research. However, it should be noted that this does not entirely address the uniqueness of every situation impeding replication.

Reflexivity also allows action researchers to justify the selection of informants when theoretical sampling is used (Glaser and Strauss, 1967) and explain distortions in the data and conclusions created by the selection of participants.

Member checks

Finally Guba and Lincoln (1981) suggest that member checks are important in proving the trustworthiness of data in new paradigm research. Member checks involve recycling categories, emerging analysis, and conclusions back through at least a subsample of respondents. In action research assessing participant confirmation and reaction to findings by use of feedback and close monitoring in the natural setting is thought to be instrumental in revealing researcher-induced distortions. In this study findings were fed back on a weekly basis, interview transcripts were returned to participants for checking and offers made to key informants to have access to the thesis as it was being written. However in reality due to transience and the passage of time leading to the loss of contact with participants, the last check on validity has not been possible. However feedback from a formal presentation of the research to participants and from the presentation of conference papers to other health professionals does not lead me to believe the findings are either untrustworthy or atypical. It could be argued that by allowing members to check the data and by giving the participants more control about what was shared, a level of trust is established which allows more relevant and valid findings to emerge.

Paradoxically, Sandelowski (1986) sees member validation as a threat to validity. She argues that members views depends upon nature of the interaction with the researcher, social norms of politeness and frank conflicts of interest and need. She questions whether the artifice of the research process itself may influence the validation process and whether the lack of convergence or consensus between member and researcher or among member themselves necessarily invalidates interpretation.

She advises caution in uncritically adopting validation strategies which hold promise of making the practices of qualitative researchers more visible and acceptable as science on the basis that they may cause as many problems as they solve. She writes:

> *"Research is both a creative and destructive process; we make things up and out of our data, but we often inadvertently kill the thing we want to understand in the process. Similarly, we can preserve or kill the spirit of qualitative work; we can soften our notion of rigor to include playfulness, soulfulness, imagination, and technique we associate with more artistic endeavours, or we can further harden it by uncritical application of rules. The choice is ours: rigor or rigor mortis."*
> (Sandelowski, 1986 p8)

Whilst in the study attempts have been made to be systematic and rigorous, for instance, in the analysis of the data, it is hoped that a fine balance is achieved between presenting the data as evidence, and maintaining the "spirit" of the data (Sandelowski, 1986). At the risk of length, endeavours have been made to present the study's methods clearly and be specific about the systematic analysis of the data in line with approaches advocated by (Miles and Huberman, 1984). By taking such an approach, opportunity is given to the reader to judge the trustworthiness of the data, whilst at the same time recognising that, in new paradigm research, "reality" is assumed to be multiple and constructed and that the nature of any work is revisionist. Given that there is always more than one version of the same story, no use was made of other researchers to check the reliability of emerging themes in the data analysis. Instead the data are presented in detail in context in order that the reader can judge the relevance of the findings to themselves in their own unique practice situation.

ETHICAL ISSUES

Ethical issues are explored in more detail in Chapter 10. It is argued that given the nature of the researcher-participant relationship plus the focus on changing practice, action research deals with sensitive issues and therefore requires special consideration of the ethics involved. In carrying out this study promises of anonymity and confidentiality were given and attempts were made to give ownership of the findings to participants. However in the reality of practice this was found to be a simplistic approach and future action research studies would benefit from exploring these issues in more detail.

SUMMARY

The chapter began by describing the action research approach taken in the study in terms of its democratic impulse, collaborative nature, evaluative methods and contribution to the body of knowledge. By drawing on the strengths of a variety of action research approaches from the more technical to the more emancipatory in nature, the study can best be described as eclectic and pragmatic. It is argued in the thesis that there are strengths and weaknesses in each approach and that eclecticism is preferred in order that studies can be tailored to suit the unique context of the practice situation being

explored. It is argued that the more modern understandings of action research in education, based on empowerment and critical theory development, are less appropriate for health care settings. Finally the chapter describes in detail the study's aims and objectives. The participants involved, data collection tools, and methods of analysis so that the reader will be able to judge the quality of the findings described in the following chapter.

INTRODUCTION TO THE FINDINGS

The findings constitute an analysis of three sets of data. They are the data reflecting the health professionals' perceptions of lay participation in care, data reflecting the changes achieved during the study and data reflecting the particular difficulties of changing health care practice. These three data sets are presented in separate chapters (Chapters 6, 7 and 8) whilst the conclusions are discussed in relation to the literature in Chapter 9.

Clearly, as with all case studies, the findings cannot be generalised to the wider population. However, by giving a rich and contextualised account of the findings, the reader is invited to judge their relevance in respect of their own practice.

Because a multi-method approach was taken several different data sets have been produced. Each data set has been systematically analysed and reduced to tabulated summaries for the purpose of presentation (see Appendices XVIII - XXIV). By giving such explicit detail of the findings, it is argued that the reader should be in a better position to judge the trustworthiness of the data (Miles and Huberman, 1984). Whilst they do not necessarily advocate that findings are presented in text format, the combination of text and illustrative tables has been used within the thesis in an attempt to preserve, as far as possible, the qualitative nature of the data. Thus, as with all other aspects of the thesis, an eclectic approach has been taken in the presentation of the findings. Where possible, descriptive statistics have been used to add an extra dimension to the data. For instance, whilst analysis of the Patient and Family Participation in Nursing Care Scale suggests there is no significant difference in attitude between the groups studied (nurses, medics, paramedics) it was felt that the use of descriptive statistics would further illuminate the point and perhaps detect more subtle differences between the groups. Issues raised by at least 25% of any one group are described in the main body of the thesis. However this reporting should not marginalise other issues which are raised with less frequency and details of these are available to the reader in the data set summaries found in the appendices. It is acknowledged that an issue raised by one articulate participant may be as much, if not more, important to the reader than other issues raised by the whole group. However, given the need to be selective in the presentation of data in the main body of the thesis, a pragmatic approach has been taken.

As described in the previous chapter, issues emerging from the study were fed back to participants in the course of the action research study by way of weekly

discussions and occasional presentations. It is argued that the participants' acceptance of these findings further strengthens their validity. However, it is worth noting that participants were not able to comment on the completed thesis. The thesis was written several years after the period of data collection and thus it was possible to have it verified by only one key participant, that is the new charge nurse. Having read aspects of the thesis she has commented:

> *"The description of the climate at the time brought back all the frustrations I felt then - definitely a 'true' picture ..... Having read the story straight through, it is very much as I remember it. There wasn't anything I wanted to take issue with".*
> (personal communication, 1994)

Whilst acknowledging the existence of multiple accounts in research (Sandelowski, 1993), the findings are presented in the belief that they are nonetheless trustworthy.

CHAPTER 6

HEALTH PROFESSIONALS' PERCEPTIONS OF LAY PARTICIPATION IN CARE

INTRODUCTION

The chapter explores the health professionals' perceptions of lay participation in care. It draws on data from both Brooking's (1986) "Patient and Family Participation in Nursing Care Scale" and from interviews and field notes based on participant observation. Because there had been a tendency to use structured tools (Pankratz and Pankratz, 1974; Citron, 1978; Linn and Lewis, 1979; Brooking, 1986) and attention drawn to their limitations (Brooking, 1986), a multi-method approach to examining this concept has been adopted. Moreover, the need to explore other health professionals' views, that is medics and paramedics, has been recognised because thus far only nurses' attitudes towards patient and family participation in nursing care in hospital have been examined (Brooking, 1986).

Key issues arising from the triangulation of the different data sets of data informing the health professionals' perceptions of lay participation in care are also reported. It is suggested that readers refer to the appendices for more detailed reporting of the different data sets ("Patient and Family Participation in Nursing Care Scale" - Appendix XVIII; Initial Interviews - Appendix XIX; Exit Interviews - Appendix XX; Senior Nurse Managers (DN) Interviews - Appendix XXI; and Field Notes - Appendix XXII).

The chapter begins by reporting on what was found in relation to health professionals' perceptions of lay participation in care using the Patient and Family Participation in Nursing Care Scale. It then goes on to report on the relevant data from the interviews and finally other appropriate data taken from the field notes.

SUPERFICIAL PERCEPTIONS : FINDINGS FROM THE MODIFIED PATIENT AND FAMILY PARTICIPATION IN NURSING CARE SCALE

As described in the previous chapter, the Patient and Family Participation in Nursing Scale is a self completion questionnaire, designed to examine current practices, opinions and attitudes towards patient and family participation in nursing care (see Appendix XIII). Whilst the questionnaire consists of seven sections, findings from the sections 4, 5, 6 and 7 do not directly relate to professionals' perceptions of lay

participation in care and so are not reported in this chapter. A total of sixty six questionnaires were distributed of which fifty one were returned, giving a response rate of 77%.

Findings from the questionnaire in the present study were compared with findings from Brooking's (1986) study to establish if the members of the multidisciplinary team under study were significantly different in attitude towards lay participation in care compared with other health professionals previously studied. These findings are presented as contextual detail, in order that the reader can judge, to some extent, the significance of the findings to the wider population.

Comparison of findings: more positive in attitude than Brooking's (1986) group

Section 1 of the questionnaire was completed by all the multidisciplinary team and examined "attitudes towards patient and family participation in nursing care". Since this part of the questionnaire had been modified by removal of the "don't know" category, the data could not be directly compared and only positive and negative trends were explored. Furthermore, it was not possible to explore how significant these trends were using statistical tests. Caution must therefore be exercised in interpreting the results. However, overall it would appear that the multidisciplinary team held more positive attitudes towards patients, family and friends participating in nursing care compared with the professional group of nurses in Brooking's (1986) earlier study.

Table 6 lists all the items in section 1 of the questionnaire and indicates the related subscale (Patient Planning, Relative Planning, Patient Implementation and Relative Implementation) to which each item belongs. Using the score system described in Chapter 5's section on "Analysis of Patient and Family Participation in Nursing Care Scale", points have been allocated to indicate whether the multidisciplinary team under study held either more positive or more negative attitudes towards each item, compared with the respondents in Brooking's study. Table 6 shows the items being ranked in order of greatest change in positive attitude to greatest change in negative attitude and demonstrates an overall positive trend in attitudes (overall score: +63) when the scores are combined for each item.

Table 6: Attitudes Towards Patient and Family Participation in Care Scale - comparison of findings with Brooking's study

Items in rank order from the greatest change in positive attitude to the greatest change in negative attitude for the multidisciplinary team compared with the nurses in Brooking's (1986) study.

Rank	Item	Sub-scale	Points*
1	6. If patients are well enough they should be allowed to keep their own medicines in their lockers, and take them as prescribed.	B	+10
2	18. It will only lead to problems for the nurses if relatives are allowed to do too much for the patient	D	+8
3	21. Relatives must accept that nurses have the training and experience to assess the patients needs without interference from the family.	C	+7
4	4. When nurses are considering what is best for a particular patient, they should ask him what he prefers.	A	+6
5	2. When a patient is first admitted, the nurse should ask him which of his problems and needs he regards as most important.	A	+5
5	14. It is always the nurses responsibility to decide on the most suitable time to renew the patient's bandage	A	+5
5	16. If a patient has a skin disease, the nurse should apply the ointment to ensure that it is rubbed in properly	B	+5
8	1. The essence of nursing is doing things for people to enable them to rest and relax in hospital	B	+4
8	10. Patients who are well enough should be allowed to write their own charts of how much fluid they are drinking each day.	B	+4
8	17. As far as possible, patients should be allowed to decide for themselves when they want to wash and bath.	A	+4
11	15. Relatives must accept that they are not entitled to do anything for the patient while he is the responsibility of the hospital.	D	+3
12	3. Relatives have a right to know what is being done to their "nearest and dearest" by the nursing staff.	D	+2
12	5. Information from a spouse about the patient's normal life style helps nurses to assess what care will be required.	C	+2
12	7. Patients must accept that whilst in hospital they have no right to question nurses' decisions about what needs to be done for them.	A	+2
12	24. Most patients are happy to hand over to the nurses complete responsibility for deciding what care they require.	A	+2
16	19. If a patient is going to need care at home, the nurses should teach his wife how to look after him while he is still in hospital.	D	+1
16	23. In planning a course of rehabilitation after a stroke, the nearest relatives should be invited to contribute their ideas	C	+1
18	12. Patients are entitled to do things for themselves as long as they feel well enough, and provided it is medically safe.	B	0
18	13. It is up to the nurses to assess how often patients need to wash their hair whilst in hospital.	A	0
20	9. Even if it would be quicker for a nurse to dress an elderly lady, she should try to encourage the old lady to do it herself.	B	-1
20	11. Before an operation the implications and risks of surgery should be discussed with the patient's nearest relative.	C	-1
20	20. When a child is in hospital his mother should be encouraged to wash and feed him, provided this is medically safe.	D	-1
23	8. Nurses should encourage patients to be as independent as possible.	B	-2
24	22. It is good for both patients and nurses if relatives can help with simple tasks like giving the patient a cup of tea.	D	-3
	Overall score		+63

*: "+" indicates positive trend; "-" indicates negative trend
Subscale A: Patient planning Subscale B: Patient implementation
Subscale C: Relative planning Subscale D: Relative implementation

From Table 6 it can be seen that the multidisciplinary team compared with Brooking's study group appeared to be generally more positive to patients being involved in the planning and implementation of care (items 6, 18, 21, 4, 2, 14, 16) and where more negative views were shown, these tended to occur in the Relative Planning and Implementation Subscales and the Patient Implementation Subscale (items 22, 8, 9, 11, 20).

Similarly for Section 2 of the questionnaire ("Care Activities in Hospital" Scale), with the exception of two items in the "Could be done by patient" list (items 3 and 4) and one item in the "Could be done by relative" list (item 8), the multidisciplinary team showed a more positive attitude compared with the professional group of nurses in Brooking's study. In this section 20 common nursing procedures were listed and respondents were asked to indicate by ticking boxes whether or not they considered patients and/or relatives would be able to carry out each of the procedures. As in Brooking's study, a tick was seen as displaying a positive attitude towards lay participation in care and as there were no modifications made to this section of the questionnaire the results can be compared directly. Table 7 indicates the differences in percentages between the two groups ticking each item. A more positive attitude in the multidisciplinary team compared with Brooking's group is indicated by a positive percentage difference and a more negative attitude is indicated by a negative percentage difference. Table 7 also demonstrates the rank order from the greatest change in positive attitude to the greatest change in negative attitude for both the "Could be done by patient" and "Could be done by relative" results.

Compared with Brooking's group the multidisciplinary team appeared to differ more in opinion towards both relatives getting involved in hospital care (average increase per item +25.49%) and patients getting involved in care (average increase per item +14.23%) (See Table 7). In particular, it can be seen that the multidisciplinary team under study held more positive attitudes (>25% difference when compared with Brooking's group) towards items in the "Could be done by relative" list (11 items: 12, 18, 20, 15, 19, 5, 1, 13, 2, 10, 6), whereas in the "Could be done by patient" list, only 4 items reveal a greater than 25% change in attitude (items: 16, 20, 13, 5). It appears therefore that compared with Brooking's group, whilst the multidisciplinary team held, overall, more positive attitudes towards the concept of lay participation in care there is perhaps some hidden concern being expressed about the involvement of relatives arising from the data in both sections 1 and 2 of the questionnaire.

Table 7: Care Activities in Hospital Scale - comparison of findings with Brooking's study

Table shows rank order of items and percentage differences between the multidisciplinary team compared with the nurses in Brooking's (1986) study indicating positive and negative changes in attitude between the two groups.

Could be done by patient		"Care Activities in Hospital" Scale	Could be done by relative	
Rank	% diff	Item	% diff	Rank
11	+12	1. Filling in the fluid chart	+37.7	7
11	+12	2. Applying ointment to the patient's skin	+33.5	9
20	-5	3. Dressing or undressing the patient	+7.8	17
19	-4.3	4. Cleaning the patient's teeth or mouth	+5	18
4	+25.1	5. Bringing or removing bedpan or bottle	+39	6
5	+24.9	6. Taking the pulse	+25.8	11
18	+2.9	7. Helping the patient to eat or drink	+4.7	19
16	+3.7	8. Brushing the patient's hair	0	20
14	+8.7	9. Helping the patient walk to the toilet	+9.7	15
8	+14.1	10. Testing the urine	+27.5	10
15	+5.6	11. Giving an injection	+21.6	12
7	+20.2	12. Rubbing the patient's back or bottom	+50	1
3	+28.3	13. Giving a suppository	+35.9	8
9	+13.5	14. Tidying the bedclothes or pillows	+9.2	16
13	+11.5	15. Washing the patient in bed	+41.5	4
1	+40.3	16. Helping the patient in or out of bed	+18.1	13
17	+3.2	17. Making him comfortable in bed or chair	+11.1	14
6	+24.5	18. Putting in ear-drops or eye-drops	+49.2	2
10	+12.6	19. Assisting him taking a bath	+39.7	5
2	+30.9	20. Taking the temperature	+42.8	3
	+284.7	**Overall total increase in scores**	**+509.8**	
	+14.23	**Overall average increase in score per item**	**+25.49**	

Turning to Section 3 of the questionnaire, this was completed by thirty one members of the multidisciplinary team (qualified nurses n=14; learner nurses n=17). The medics and paramedics were not given this section as it was designed to examine the organisation of nursing as opposed to other aspects of health care. Following the format used in Brooking's study, responses indicating "care organised to allow patient and family participation" were interpreted as positive attitudes to lay participation in care. Thus items 1, 2, 3 and 8 required the respondent to answer closer to "never" and items 4, 5, 6, and 7 required the respondent to answer closer to "always". As with Section 1 of the questionnaire, scores could not be compared directly since the questionnaire had been modified by removal of the "don't know" category. However, as before, it is possible to award correspondingly points in relation to whether the nurses in the present study showed more positive or negative attitudes compared with the nurses in Brooking's study. In this way trends can be explored rather than actual values compared. Table 8 shows an overall score of +4 indicating that nurses in the study held only marginally

more positive attitudes towards "patients, their family and friends becoming involved in nursing care" compared with the professional group in Brooking's (1986) study. Table 8 also shows the items from the Nurses' Organisation of Care Scale in rank order from greatest change in positive attitude to greatest change in negative attitude for the group of nurses in the present study compared with those in Brooking's study.

Table 8: Nurses Organisation of Care Scale - comparison of findings with Brooking's study

Items in rank order from the greatest change in positive attitude to the greatest change in negative attitude for the nurses (qualified and unqualified) compared with the nurses in Brooking's study.

Rank	Item	Points
1	8. I tend to decide what needs to be done for the patient without asking for his/her views.	+4
2	5. I encourage the relatives to help with the patient's nursing care in various ways.	+3
3	1. I plan the nursing care without asking the patient's family what they think.	+1
3	3. I discourage the family from doing anything for the patient while he/she is in the care of the hospital.	+1
5	6. I encourage my patients to be as independent as possible, and help themselves as far as their illness allows.	0
6	2. I tend to do everything for my patients, even if they could manage themselves.	-1
7	4. I encourage the patient to express his/her views when decisions about his/her nursing care have to be made.	-2
7	7. I try to consult the relatives when decisions about the patient's care have to be made.	-2
	Overall score	+4

Table 8 illustrates that where the nurses in the present study were more positive than the nurses in Brooking's study, it tended to occur with items 8, 5, 1, and 3 and where the nurses in the present study were more negative, compared with Brooking's nurses, it tended to occur with items 2, 4, and 7; with no difference in trend of attitude for item 6. It is noteworthy that the greatest positive changes in attitude for the group of nurses in the present study concerns the involvement of the patient in decision making about what needs to be done and the involvement of the relatives in helping with the patients' nursing care. However the greatest change in negative attitude for the group of nurses in the present study concerned the involvement of the relatives in decision making and the involvement of the patients in decision making about his or her nursing care. The

indication here is that the nurses in the present study may be confused about involving patients in decisions about nursing care since it was not only the area of greatest positive change, but also the area of greatest negative change in attitude, compared with those in Brooking's study. However it would appear also that the nurses in the present study, whilst more positive about involving relatives in implementing care, are nonetheless more cautious about involving them in the decision making processes.

Having explored the difference between the multidisciplinary team's perception of lay participation in care compared with the health professionals in Brooking's study, it was decided to compare the findings between the professional groups, that is, nurses, medics and paramedics, within the multidisciplinary team. Whilst overall the health professionals had shown positive attitudes towards the concept of lay participation in care, it was considered important to establish whether, or not, within the multidisciplinary team respondents held similar views. A review of the literature had revealed that in the past only nurses' perceptions of lay participation in care had been explored (Brooking, 1986).

Comparison of findings: no difference in attitude between nurses, medics and paramedics

An analysis of variance between the subgroups (qualified nurses n=14; learner nurses n=17; medics n=11; paramedics n=9) in the multidisciplinary team was measured using the Kruskal-Wallis test for Section 1 ("Attitudes Towards Patient and Family Participation in Care" Scale) and for Section 2 ("Care Activities in Hospital" Scale). The results from these analyses of variance are tabulated below (see Tables 9 and 10). Both these tables show the mean ranks, Kruskal-Wallis test statistic, and p-values that have been corrected for ties. Section 3 of the questionnaire ("Nurses Organisation of Care" Scale) was completed only by the nurses and so an analysis of variance between the qualified nurses and the learners was measured using a 2-tailed Mann-Whitney test. Table 11 shows the findings for Section 3 of the questionnaire and indicates the mean ranks, Mann-Whitney test statistic, and p-values that have been corrected for ties.

Table 9: Attitudes Towards Patient and Family Participation in Care Scale - analysis of variance between subgroups

Item	Mean Ranks	Mean Ranks	Mean Ranks	Mean Ranks	Kruskal Wallis Test Statistic	p-value
	Qualified Nurses	Learner Nurses	Medics	Paramedics		
1	28.62	27.03	17.28	21.00	5.6011	0 1327
2	19.36	29.97	24.35	27.89	6.1358	0.1052
3	25.19	26.09	23.14	27.72	0.6688	0.8805
4	29.25	28.50	18.82	25.00	5.3566	0.1475
5	25.07	28.50	26.73	21.83	1.7735	0.6207
6	29.43	27.71	16.85	24.83	5.8387	0.1197
7	27.54	30.00	23.73	18.83	6.2388	0.1006
8	27.96	29.74	19.00	21.89	6.2311	0.1009
9	27.29	32.12	14.18	26.89	13.1122	0.0044*
10	30.25	34.68	15.55	15.78	21.3697	0.0001*
11	26.79	25.71	23.64	28.22	0.6467	0.8857
12	30.21	30.00	21.27	17.67	8.4732	0.0372*
13	24.92	28.09	18.09	25.39	4.4638	0.2155
14	23.46	25.78	27.59	25.61	0.6739	0.8793
15	28.86	25.71	26.00	19.33	3.2394	0.3562
16	29.15	26.53	20.30	21.33	4.5573	0.2072
17	23.96	32.03	22.14	19.50	7.5442	0.0564
18	27.21	28.00	23.35	20.50	2.9489	0.3996
19	27.39	29.00	22.59	22.33	2.6704	0.4453
20	26.36	29.09	21.45	25.17	2.8644	0.4130
21	27.54	26.00	23.50	23.61	1.0690	0.7846
22	24.64	28.03	26.90	20.50	2.2499	0.5222
23	29.00	27.18	22.68	23.17	1.9937	0.5737
24	27.04	23.09	23.27	30.56	2.6093	0.4559

Mean ranks, Kruskal-Wallis test statistic, and p-values that have been corrected for ties.
* isolated items significant with a 5% chance of error

Table 10: Care Activities in Hospital Scale - analysis of variance between subgroups

Item	Mean Ranks	Mean Ranks	Mean Ranks	Mean Ranks	Kruskal Wallis Test Statistic	p-value
	Qualified Nurses	Learner Nurses	Medics	Paramedics		
1A	28.96	26.50	23.50	23.50	4.3012	0.2307
1B	25.00	25.00	29.64	25.00	7.4212	0.0596
1C	24.79	26.50	26.77	26.00	0.2135	0.9754
2A	27.14	26.50	25.82	23.50	1.3495	0.7174
2B	27.32	25.50	25.50	25.50	2.6429	0.4500
2C	25.46	24.50	31.59	22.83	3.9916	0.2624
3A	28.46	26.00	25.32	23.00	2.4856	0.4779
3B	24.00	24.00	28.64	29.67	6.7054	0.0819
3C	24.82	26.00	29.95	23.00	3.9574	0.2661
4A	27.96	27.00	22.50	25.33	2.6708	0.4452
4B	24.82	26.00	25.32	28.67	1.2863	0.7324
4C	21.64	27.00	27.27	29.33	2.8053	0.4226
5A	24.50	27.50	26.82	24.50	2 6515	0.4485
5B	20.46	24.00	26.59	37.67	10 6083	0.0140*
5C	24.96	31.50	24.14	19.50	7.5234	0.0570

Table 10: Continued

Item	Mean Ranks	Mean Ranks	Mean Ranks	Mean Ranks	Kruskal Wallis Test Statistic	p-value
	Qualified Nurses	Learner Nurses	Medics	Paramedics		
6A	26.00	26.00	26.00	26.00	0.0000	1.0000
6B	23.07	28.00	27.05	25.50	1.4170	0.7016
6C	21.75	28.50	29.86	23.17	4.0408	0.2571
7A	29.46	25.50	24.00	24.00	5.2622	0.1536
7B	24.61	23.00	22.45	38.17	10.2750	0.0164*
7C	26.00	26.00	26.00	26.00	0.0000	1.0000
8A	27.96	27.00	22.50	25.33	2.6708	0.4452
8B	25.64	28.00	24.32	24.83	1.2899	0.7315
8C	26.00	26.00	26.00	26.00	0.0000	1.0000
9A	28.14	26.00	24.50	24.50	2.9762	0.3953
9B	21.11	25.50	25.91	34.67	6.1838	0.1030
9C	23.00	27.50	25.32	28.67	3.3895	0.3354
10A	25.50	27.00	25.50	25.50	2.0000	0.5724
10B	21.96	25.50	28.09	30.67	3.0725	0.3806
10C	22.11	29.50	24.59	27.17	2.7421	0.4331
11A	26.00	26.00	26.00	26.00	0.0000	1.0000
11B	21.43	27.00	29.05	27.50	2.7315	0.4349
11C	21.93	24.50	31.86	28.00	4.2610	0.2346
12A	25.82	25.50	28.64	24.00	2.4437	0.4856
12B	23.07	26.50	24.73	31.17	2.6778	0.4440
12C	25.32	26.50	28.14	23.50	1.9975	0.5729
13A	28.14	26.00	24.50	24.50	2.9762	0.3953
13B	24.29	23.00	23.95	36.83	8.5589	0.0358*
13C	23.93	26.50	26.91	27.17	0.5168	0.9152
14A	27.64	27.00	24.00	24.00	2.8116	0.4216
14B	25.29	24.00	24.95	32.17	3.0071	0.3905
14C	25.00	28.00	25.00	25.00	4.0816	0.2528
15A	26.82	26.50	25.00	25.00	1.3484	0.7177
15B	26.07	26.50	20.77	31.33	3.4476	0.3276
15C	23.00	27.50	27.64	25.83	2.8171	0.4207
16A	26.82	26.50	25.00	25.00	1.3484	0.7177
16B	22.57	24.50	28.86	30.67	3.5514	0.3142
16C	22.50	28.50	27.14	25.33	3.7682	0.2876
17A	26.32	26.00	26.82	24.50	0.7914	0.8515
17B	22.57	23.00	31.18	30.67	5.8746	0.1179
17C	25.50	25.50	27.82	25.50	3.6364	0.3035
18A	26.82	26.50	25.00	25.00	1.3484	0.7177
18B	21.11	28.50	28.23	26.17	3.0217	0.3883
18C	22.64	28.00	30.59	21.83	4.6474	0.1995
19A	26.32	26.00	26.82	24.50	0.7914	0.8515
19B	22.57	24.50	28.86	30.67	3.5514	0.3142
19C	23.50	28.00	28.14	23.50	4.4664	0.2153
20A	26.00	26.00	26.00	26.00	0.0000	1.0000
20B	23.75	30.50	22.59	25.17	3.4187	0.3315
20C	23.61	31.00	21.45	25.83	4.4616	0.2157

A: "Could be done by nurse" B. "Could be done by patient" C: "Could be done by relative"
Mean ranks, Kruskal-Wallis test statistic, and p-values that have been corrected for ties.
* isolated items significant with a 5% chance of error

Table 11: Nurses' Organisation of Care Scale - analysis of variance between subgroups

Item	Mean Ranks	Mean Ranks	Mann-Whitney Test Statistic	p-value
	Qualified Nurses	Learner Nurses		
1	14.85	16	-0.3908	0.6959
2	15.79	16.18	-0.1364	0.8915
3	14.18	17.50	-1.9756	0.0482*
4	16.21	15.82	-0.1290	0.8973
5	14.18	17.50	-1.1286	0.2591
6	13.61	17.97	-1.5910	0.1116
7	14.36	17.35	-1.0266	0.3046
8	15.25	16.62	-0.4809	0.6306

Mean ranks, Mann-Whitney test statistic, and p-values that have been corrected for ties.
* isolated items significant with a 5% chance of error

As shown in the above tables it can be seen that there is no significant difference between the subgroups of the multidisciplinary team except for isolated items. Such isolated items showing significance do not warrant further comment (see Table 12).

Table 12: Patient and Family Participation in Nursing Care Scale - summary of cross tabulation findings for significant isolated items

Section 1: "Attitudes Towards Patient and Family Participation in Care" Scale		
Item	Statement	Response
9.	Even if it would be quicker for a nurse to dress an elderly lady, she should try to do it herself.	Learner Nurses "strongly disagreed" Medics "agreed"
10.	Patients who are well enough should be allowed to write up their charts of how much fluid they are drinking each day.	Qualified Nurses "strongly disagreed" Medics and Paramedics "agreed"
12.	Patients are entitled to do things for themselves as long as they feel well enough, and provided that it is medically safe.	Qualified Nurses "strongly disagreed" Medics and Paramedics "agreed"
Section 2: "Care Activities in Hospital" Scale		
Item	Statement	Response
5.	Bringing or removing bedpan or bottle (Could be done by patient)	Nurses "agreed" Medics "agreed" and "disagreed" Paramedics "disagreed"
7.	Helping patient to eat and drink (Could be done by patient)	Nurses and Medics "agreed" Paramedics "disagreed"
13.	Giving a suppository (Could be done by patient)	Nurses and Medics "agreed" Paramedics "disagreed"
Section 3: "Nurses' Organisation of Care" Scale		
Item	Statement	Response
3.	I discourage the family from doing anything for the patient while h/she is in care of the hospital	Qualified Nurses "sometimes" Learner Nurses "never"

Thus participants expressed overall positive attitudes towards lay participation in care. The group of health professionals in the present study tended to hold, overall, more positive attitudes towards the concept than Brooking's professional group. In particular, the study group appeared to be generally more positive to patients being involved in the planning and implementation of care (items 6, 18, 21, 4, 2, 14, 16) whilst negative views tended to occur in the Relative Planning and Implementation Subscales and the Patient Implementation Subscale (items 22, 8, 9, 11, 20).

Findings also showed that in general the nurses, medics and paramedics held similar views in respect of lay participation in care. An analysis of variance between the subgroups of the multidisciplinary team shows that there is no significant difference between the subgroups except for a few isolated items. These isolated items (Items 9, 10 and 12 on the "attitudes towards patient and family participation in care") might suggest that the nurses themselves are less positive to patients being involved in care compared with the medics and paramedics. Because this can only be demonstrated in a few isolated items, the finding should be viewed with caution. Again there is no significant difference between subgroups in response to the "care activities in hospital" section except for a few isolated items (items 5, 7, 13). This seems to indicate that the paramedics might hold more cautious views about patients being more involved with the practical aspects of nursing care. The "nurses' organisation of care" section was completed only by the nurses but an analysis of variance between the qualified nurses and learner nurses reveals that there is again no significant difference, except for one isolated item (item 3). Whilst caution should be heeded in drawing any conclusions from an isolated item, it is interesting to note that the qualified nurses show a degree of caution, compared with the learner nurses, when involving the family and friends in hospital care.

Given that overall the Patient and Family Participation in Nursing Care Scale shows that the health professionals hold positive attitudes, it is interesting to compare these data with the interview data which indicate that when questioned more closely the health professionals have a limited understanding of lay participation in care and hold some serious reservations about applying the concept to their health care practice.

PROBING MORE DEEPLY: FINDINGS FROM THE INTERVIEW DATA

Analysis of the Patient and Family Participation in Nursing Care Scale demonstrates clearly that the health professionals in the present study hold positive views towards lay participation in care and do not differ significantly in their views when comparing the different sub groups (nurses, medics and paramedics). However, in

examining the interview data the following section argues that the use of structured tools to measure complex phenomena is inappropriate.

Interviews took place at the beginning of the project or as new staff joined the multidisciplinary team (Initial Interviews: Nurses=18; Medics=14; Paramedics=13) and at the end of the project or as staff left the ward to work elsewhere (Exit Interviews: Nurses=8; Medics=10; Paramedics=7). In the course of the study interviews also took place with Senior Nurse Managers (District Nursing) (n=8). This section only draws on those data which inform the health professionals' understanding of lay participation in care. However, fuller accounts of the data from the initial interviews, exit interviews and Senior Nurses Managers (District Nursing) interviews can be found in Appendices XIX, XX and XXI respectively.

An issue emerging from the interviews and not detected by the Patient and Family Participation in Nursing Care Scale is the health professionals limited understanding of lay participation in care.

Limited understanding

At interview, despite being theoretically in favour of lay participation in care, participants found it difficult to articulate what they understood by it. Their answers reflect a superficial understanding of the concept with no recognition of it being a major thread of health promotion. Whilst the literature on participation in care focuses on patient empowerment and changes in relationship between professional and lay people based on such concepts as "self help", "demedicalisation or deprofessionalisation" and democratisation" (McEwen et al., 1983), participants tended not to draw out such issues. Instead most participants, and in particular medics (Exit Interviews: N: 50%; M: 90%; P: 50%; J: 65%), remained unfamiliar with the concept and spoke in vague terms about patients and relatives being involved in care without specifying what this really meant. For instance, one medic said at exit interview:

> *"Well, it's a very general term and I have never really fully understood exactly what was meant. I assume it means involving people's relatives in their care, either in hospital or training them to be able to continue the hospital-type care at home."*
> (Medic: M25(E)p15)

When defining lay participation in care, participants tended to focus on lay people being involved in practical tasks such as giving treatments (Exit Interviews: N: 20%; M:

40%; P: 33%; J: 31%). In particular medics focused on lay people assisting with the activities of daily living (Exit Interviews: N: 10%; M: 60%; P: 0%; J: 27%) and on the practical task of drug taking (Exit Interviews: N: 0%; M: 30%; P: 17%; J: 15%) . Others saw it as being about keeping lay people better informed, in particular about what is happening to them (Exit Interviews: N: 20%; M: 30%; P: 33%; J: 27%), with medics also focusing on informing lay people about what is wrong with them (Exit Interviews: N: 10%; M: 40%; P: 17%; J: 23%). Several medics actually stated that they were unclear on the meaning of lay participation in care, finding the concept intangible (Exit Interviews: N: 20%; M: 40%; P: 17%; J: 27%) and being uncertain as to who might wish to participate (Exit Interviews: N: 20%; M: 30%; P: 0%; J: 19%). For some medics and paramedics it is seen as being more of a nursing issue (Exit Interviews: N: 0%; M: 50%; P: 33%; J: 27%). This is interesting as several nurses commented that they felt unprepared as it had not been part of their training (Exit Interviews: N: 30%; M: 10%; P: 0%; J: 15%). In contrast some paramedics said that the concept was indeed familiar and had been very much part of their own training (Exit Interviews: N: 10%; M: 20%; P: 50%; J: 23%). What ever the claims, very few actually brought out the theme of patient empowerment in their definitions and there was a sense in which some medics actually expected to be in control of decision making (Exit Interviews: N: 0%; M: 30%; P: 0%; J: 12%) . As one medic said at his exit interview:

> *"Well, I always tend to think of it as more of a nursing aspect, i.e. the general activities that they would be giving - washing, dressing, going to the toilet and things like that, going on to taking medicines and having more of an idea of their illness and treatment ..... Doctors tend to assume that we are the ones who decide what sort of treatment they have. Whether ..... mean, in general you take the wishes of the patient concerned, but ultimately we alter the management, or at least we are aware of what is going on. I suppose in the way that we see what the management options are and would ask the patient what they thought - I suppose that is participation and our role in some of the medical issues."*
> (Medic: M30(E)p1)

In fact medics tended to view lay participation in care more as a cost effective measure to help with shortages in nursing staff (Exit Interviews: N: 20%; M: 40%; P: 0%; J: 23%). Interestingly some nurses recognised lay participation in care to be less concerned with tasks and to be more of a general approach to care facilitating self help (Exit Interviews: N: 40%; M: 10%; P: 0%; J: 19%) whilst the paramedics viewed it as a means of helping lay people to gain confidence and be more quickly and better prepared for their discharge (Exit Interviews:: N: 10%; M: 20%; P: 33%; J: 19%).

Some participants found it difficult to think how lay participation in care might be implemented and seemed reluctant to relinquish their professional roles. As one nurse said at her initial interview:

> *"I think it's a really good idea ..... and at the same time I think it's difficult, or I find it difficult to know what sort of tasks to give them to do and sometimes I find myself hanging on to all because that's my role and you know it's easy to hide behind the sort of nurse's role, I can do all this and get on and do it, and it is more difficult and perhaps takes longer to involve them in care."*
> (Nurse: N4(I)p2/3)

Some paramedics feared it was an idealistic concept which would be difficult to put into practice (Exit Interviews: N: 0%; M: 20%; P: 33%; J: 15%). Some nurses feared that the concept had not been socially accepted and might induce guilt in people who did not wish to participate (Exit Interviews: N: 30%; M: 0%; P: 0%; J: 12%).

Questions asked about lay participation in care did not differentiate between patients, and their family or their friends becoming more involved in care in hospital. It was thought such a differentiation would make the interviews too unwieldy and was not considered to be important when looking at health professionals' general attitudes to lay participation in care. However, it is interesting to note that there was a tendency amongst professionals to concentrate on issues around family and friends participating in care rather than issues concerning patient self care. The reason for this is unclear. It may be due to participants assuming that patients are already involved in care or due to health professionals having more anxiety and concern about involving family and friends in care and therefore needing to discuss the issue in more depth. Certainly as reported earlier there is some evidence to support this from the results of Patient and Family Participation in Care Scale. It is also interesting to note that none of the health professionals identified with lay participation in care at the level of public participation (see Chapter 2).

It appears therefore that there are some important differences between groups in their attitude towards lay participation in care. Differences in familiarity with the concept might possibly been due more to different emphases within educational programmes than to shared experience in health care practice, as few participants were able to give clear and consistent details of where they had encountered lay participation in care during their practice.

Lack of previous experience

At their initial interview health professionals were asked about their previous practical experience of lay participation in care. Several medics stated that they had not had any previous experience of lay participation in care (Initial Interviews: N: 17%; M: 29%; P: 0%; J: 15%) and said that they had not previously come across the concept (Initial Interviews: N: 0%; M: 36%; P: 8%; J: 13%). As one medic said at his exit interview:

> *"I mean at this moment it's not something that's been introduced in the whole hospital so it's difficult. People are only on this ward for a very short period of time and they know that when they move on they're not going to be involved in lay participation in care on the ward, and they weren't on previous wards that they were on, so it's something you were involved with for a short period of time, they don't take it as seriously as they might if it was a policy in the hospital, you know, or a policy in medicine in general really."*
> (Medic: M26(E)p2)

By comparison, 38% of paramedics (Exit Interviews: N: 0%; M: 7%; P: 38%, J: 13%) saw it as part of their job and stated that they had come across the concept in rehabilitation (Initial Interviews: N: 11%; M: 7%; P: 38%; J: 18%). However, apart from identifying rehabilitation as an area in which they had gained experience of lay participation in care, as with the nurses and medics, they were unable to identify clearly (>25% agreement) any other situation in which they had gained the experience.

Where there were differences between the medics, nurses and paramedics it may be accounted for by the fact that nearly three quarters of the medics and half of the nurses had trained at the hospital under study, whereas none of the paramedics had trained in the hospital (Initial Interviews: N: 50%; M: 71%; P: 0%; J: 42%). It is suggested that the reason lies in the fact that lay participation in care is not really part of the ideology underpinning training at the study hospital. However, the suggestion should be viewed with caution as most participants had some previous experience of working in other hospitals (Initial Interviews: N: 44%; M: 71%; P: 69%; J: 60%).

In contrast to the hospital health professionals' lack of experience of lay participation in care, the few community nurses interviewed (n=8) appeared to be more familiar with the concept. This again demonstrates that there may be differences in attitude towards the concept amongst different professional groups, although as stated

earlier, this was not detected through the more structured means of an attitude scale such as the Patient and Family Participation in Nursing Care Scale (Brooking, 1986).

Difference in understanding between community and hospital practitioners

The Senior Nurse Manager (District Nursing) interviews revealed that community nurses had a better understanding of lay participation in care. The finding suggests that it was working in the context of a hospital that prevented professionals from involving lay people more in care. Whilst the finding should again be viewed with caution on account of the very small numbers of community nurses interviewed (n=8), nonetheless it is interesting that there appears to be a difference in attitude towards lay participation in care between the community nurses and the hospital practitioners. This may warrant further study. The community nurses interviewed perceived lay participation in care as a fundamental part of District Nursing philosophy and practice and suggested that nurses needed to develop educative and supportive roles to better prepare lay people for returning to the community after hospitalisation (SNM(DN) Interviews: 87.5%, n=7). They argued that nurses coming from hospital settings to work in community settings needed to be re-educated into new ways of thinking which emphasises lay participation in care (SNM(DN) Interviews: 62.5%, n=5). They said that the concept of lay participation in care was not familiar to hospital nurses and that it took time for them to develop a better understanding (SNM(DN) Interviews: 62.5%, n=5). Community nurses suggested there was a need for lay people to become more empowered in hospital, and argued that lay people seem to have rights in the community which are ignored in hospital settings (SNM(DN) Interviews: 50%, n=4). Thus it appears that the community nurses have a more sophisticated understanding of the concept.

Furthermore where hospital health professionals found it hard to identify where they had experienced lay participation in care, the community nurses quite clearly agreed with each other that they had gained experience of the concept through nursing patients with AIDS (SNM(DN) Interviews: 75%, n-6) and the elderly (SNM(DN) Interviews: 50%, n=4).

The majority of community nurses stated that "Nursing" was going in the right direction by making lay participation in care a professionally valued concept (SNM(DN) Interviews: 75%, n=6). However they argued that the concept was not yet socially accepted as part of normal practice and that patients generally expected to have passive roles (SNM(DN) Interviews: 50%, n=4). They questioned whether relatives would be able to take on a role of caring given their other responsibilities and feared they may

perceive it as a burden (SNM(DN) Interviews: 87.5%, n=7). They wondered if many lay people would be capable of more involvement in care on account of their age, disability, illness or intellect (SNM(DN) Interviews: 50%, n=4). They also suggested that for some patients there were not always relatives available to become involved in care (SNM(DN) Interviews: 50%, n=4). They also wondered if relatives might not want to take on care, being too frightened in case something went wrong (SNM(DN) Interviews: 62.5%, n=5), or being embarrassed at having to do intimate things (SNM(DN) or simply just not wanting to get more involved in care (SNM(DN) Interviews: 50%, n=4). On the other hand, whilst aware of these reservations they identified positively with the need for lay participation in care in practice. For instance, they felt concerned that patients were too often discharged into the community with unrealistic expectations of what services would be provided (SNM(DN) Interviews: 62.5%, n=5) and believed that lay participation in care in hospital would help prepare people for the reality of limited provision of services in the community which had been created by a scarcity of resources. They suggested that hospital health professionals needed to learn to view patients in the wider context of their family and friends (SNM(DN) Interviews: 50%, n=4). They advocated that all close family and friends should be interviewed routinely on the patient's admission to hospital to explore these relationships and also provide explanations as to what was happening in hospital (SNM(DN) Interviews: 50%, n=4). They believed it was important for health professionals in hospital to assess carefully lay people's motivation to care during such interviews (SNM(DN) Interviews: 62.5%, n=5). However, they recognised that hospital nurses will need to develop new skills in order to practice lay participation in care, and emphasised the importance of counselling skills in enabling lay people to discuss their fears and adjust to their illness (SNM(DN) Interviews: 50%, n=4).

From this analysis it can be seen there are some differences in perceptions between the hospital and the community nurses. However, there are also some similarities. The following section draws on these similarities and indicates the differences between groups by reporting on the data from the initial interviews which explored the advantages and disadvantages of this type of care from the perspective of the patient, the family, friend and the professional. These data can also be used to demonstrate that when probed more deeply at interview, health professionals, despite holding positive attitudes towards lay participation in care in theory (as measured by Brooking's attitude scale), held some reservations about the concept in reality.

Perceived advantages and disadvantages of lay participation in care

When analysing the interview data, there is an interesting difference between the groups in that the nurses agree more with each other in their views on lay participation in

care than either the medics or the paramedics. For example, when participants were asked at their initial interviews to identify advantages and disadvantages of involving patients and their family and friends in care more than 50% of nurses agreed on thirteen of the overall themes raised, compared with the paramedics who agreed at this level (that is more than 50%) on four themes only and the medics who agreed on one theme only (see Appendix XIX). Given that in the study nurses are no better equipped than any other health professional in involving patients and their family and friends in care, the finding may indicate that nurses are more familiar with the rhetoric associated with lay participation in care rather than its practice.

In support of the suggestion that health professionals are not as in favour of lay participation in care as they might at first appear, it is of interest that whilst there is no strong agreement amongst the health professionals as to the advantages of lay participation in care when viewed from the professionals' perspective, in contrast health professionals do agree (>25% of the joint group) on a few of the advantages from the patients' and relatives' perspectives. Given also that many more disadvantages are identified from the perspective of the health professional (n=67) compared with the number of disadvantages identified from the perspective of the patient (n=46) or from the perspective of the family and friend (n=41) (for details see Appendix XIX), there appears to be some evidence that health professionals hold some negative attitudes towards the concept of lay participation in care.

The following tables (Table 13 and 14) summarise the perceived advantages and disadvantages of involving patients and their family and friends in care which were raised by >25% of any one group of health professionals (nurses, medics, paramedics).

Table 13: Perceived advantages of lay participation in care - main themes from initial interviews

From Patients' Perspective	M %	P %	N %	J %
Improved outcome in long term				
Well looked after at home - continuity of care	43	46	33	40
Better standard of care				
Relative give better care - more time, more interest	43	38	33	38
Improves recovery				
Improves recovery - compliance and control over disease	29	31	50	38
Better experience of being in hospital				
Less frightened - more relaxed	21	38	33	31
Feel closer to relative than nurse	7	8	50	24
Better understanding and better informed				
More knowledgeable about illness and treatment	36	23	22	27

Table 13: Continued

From family and friends' perspective	M %	P %	N %	J %
Better experience of being a visitor in hospital				
More positive role to play - feel less inadequate	43	62	78	62
Better continuity of care at home				
More likely to continue care after discharge	21	8	44	27
Better prepared for discharge				
Know what to do after discharge		54	17	22
From professionals' perspective	**M %**	**P %**	**N %**	**J %**
Improved discharge arrangements				
Easier to make discharge arrangements	7	31	50	31
Cost effective-solves problem of lack of resources				
Economic necessity - lack of manpower and resources	43	38	11	29
Better relationship with professional				
More aware, better informed-easier to relate to	36	8	33	27

M=Medics (14), P=Paramedics (13), N=Nurses (18), J=Joint (45)

Table 14: Perceived disadvantages of lay participation in care - main themes from initial interviews

From Patients' Perspective	M %	P %	N %	J %
Invasion of Privacy and Independence				
May not like closeness with family - too personal	29	31	39	33
Lay care not as good as professional care				
May not see care as good as professional care	29	31	39	33
From Family and friends' Perspective	**M %**	**P %**	**N %**	**J %**
Unable to participate				
May work - can't visit	43	54	50	49
Intrusion on own or others life				
Takes time and effort-burden and intrusion on own life	29	54	50	44
Participation may cause more anxiety				
Frightened to take responsibility -anxious	36	46	39	40
Feel forced to get involved				
Feel forced and obliged to get involved	36	15	61	40
Participation not part of patient role				
Paid taxes - expect professional to give care	29	38	44	38
Lay care not as good as professional care				
Don't feel capable-feel might do harm	14	46	44	36
From Professionals' Perspective	**M %**	**P %**	**N %**	**J %**
Time consuming and increased workload				
Takes time to educate	36	46	50	44
Too time consuming to communicate with everyone	29	46	17	29
Interrupt ward routine and practice				
Could slow things down on the ward-interrupt routine	29	31	28	29
May get under nurses' feet	36	38	11	27

M=Medics (14), P=Paramedics (13), N=Nurses (18), J=Joint (45)

Perceived advantages

Table 13 shows that health professionals perceived the greatest advantage of lay participation in care would be that family and friends would have a better experience of being a visitor in hospital, have a more positive role to play and thus feel less inadequate. Nurses also felt that if family and friends were involved more in hospital they would be more likely to continue the care after discharge. The paramedics stressed that they would be better prepared for discharge. As one paramedic said:

> *"Well the advantages, say with the neuro patients, someone who's had a stroke, even simple things like getting from the bed to a chair can be traumatic really, very frightening, so I think the more confidence you have in the person who is lifting you over the better you feel about it and probably the more you'd be able to participate yourself. So the easier we can make it the better it is, so from that point of view getting the person who will perhaps doing that at home, practice under supervision is a good thing."*
> (Paramedic: P29(I)p3/4)

From the patients' perspective, lay participation in care was seen generally to lead to an improved long term outcome on account of it enabling more continuity of care between hospital and home. Family and friends were thought to be able to give a better standard of care having more time for, and being more interested in, the individual patient. All groups of health professionals (and nurses in particular) thought that recovery rates would improve due to better compliance and more control over disease processes. Nurses and paramedics also thought that patients would be less frightened and more relaxed in hospital. Nurses focused their belief on this being due to patients feeling closer to their family and friends than to nurses. On the other hand medics emphasised that patients were likely to have a better understanding and be better informed as a result of lay participation in care. There is not a strong consensus as to the advantages from the professionals' perspective. However, both the paramedics, and with greater frequency the nurses, stressed that it would improve and make easier patient discharge arrangements. Meanwhile, the medics and paramedics stressed there would be some cost effective benefits. Both medics and nurses highlighted that lay participation in care would also lead to a better relationship with professionals with lay people being better informed and therefore easier to relate to. The advantages were described by one medic as follows:

> *"Oh I think there are (advantages), I mean you get better feed back, they know about the patient ..... if you can have confidence that they are being well looked after at home, and involved and knowledgeable about their illness, then I think*

that makes the whole thing much easier to manage. I think problems arise when the patient comes back to the clinic and you find they've got no support, they don't really understand their illness, I think that's a disaster."
(Medic: M2(I)p5/6)

Perceived disadvantages

Table 14 indicates that health professionals perceived the greatest disadvantage of lay participation in care to be the fact that some family and friends might be unable to participate in care on account of their own work preventing them from visiting the hospital. They also questioned whether family and friends might perceive lay participation in care as an extra burden and intrusion on their own lives due to the amount of time and effort it would demand. All groups of health professionals suggested that participation may cause more anxiety in family and friends as a result of them being frightened to take on the responsibility of care. Medics and again with greater frequency the nurses, felt concerned that family and friends might feel forced and obliged to get involved. All groups suggested lay people might not view participation in care as part of the patient role. As one paramedic reflects:

"Well there may be, this is a very personal view, it's not proven in any way, but I think that sometimes people get into a kind of way of thinking that there must be something that can be done for every ill in the world so if it snows it's somebody's job to put gravel on the road and if your child doesn't talk there must be something that can be done by somebody to make it happen. A rather passive view of the world, I don't want to say that they're trying to shift their responsibility because I'm sure it's not that, or in any conscious way that, but a sort of attitude that there is a cure for all ills and that there's somebody out there, a professional person, who will be able to deal with it. And with some people there is a lack of insight into how the family runs or the way the environment is or whatever could have any effect on the child's language development or whatever. That's not to say we go around blaming parents for the way their children are, not that at all, but just in many cases you can't get very far unless you can involve all these people and some of them don't seem to see that."
(Paramedic: P22(I)p6)

Furthermore all groups questioned whether family and friends might perceive lay care as not being as good as professional care and the nurses and paramedics also wondered if family and friends might not feel capable of giving care believing that they might do harm to the patients. For instance, as one nurse said:

"Oh no, but I've got my doubts as to whether the average person in the street will want to come into hospital and start looking after their relatives and carry on at home, I think that as well as the doubts they may well feel that we're trying to transfer our responsibilities on to them, to save money, maybe it's a political thing, they might say why should we do this when you're paid to do it, we've paid our stamps and it may end up you get political arguments about what we're trying to do to save money, we've paid our national health money and we want our money's worth sort of thing. 'Cause people tend to use the social state, don't they, to full advantage now?"
(Nurse: N0(I)p14)

From the patients' perspective all groups of health professionals were concerned that patients might not want lay participation in care, seeing it as being an invasion of their privacy and independence and fearing that the care given might not be as good as professional care. On the other hand from the professionals' perspective, concern was more related to disruption of normal practice. All groups felt that lay participation in care would increase their work load as it takes time to educate people and the paramedics stressed that it is very time consuming to communicate effectively with everyone. Another central concern was that lay participation in care would interrupt and slow down ward routine and practice. Interestingly medics and paramedics expressed a concern that lay participation in care would lead to more people getting in the way of nurses doing their work but this was not identified as an issue by the nurses themselves. There was the suggestion that there might be hidden reasons as to why health professionals might feel negative about lay participation in care. As one medic commented:

"I think all of us are probably a little reluctant to allow relatives, non-members of our professions, to be involved in patient care ..... we might tend to think right, things are probably going to get messed up, our routine is going to be messed up, we'll have to share all our idiosyncrasies and our frustrations and all the rest with the relatives and they'll see what we're really like, whereas we want to retain our detachment, we want to retain our respectability and so there might be quite a few hidden reasons why the flesh is weak."
(Medic: M7(I)p9/10)

From the above it can be seen that when interviewed health professionals were not always in agreement about their views on lay participation in care and whilst they still expressed some positive aspects in relation to lay participation in care, when probed more

deeply they revealed some serious concerns which have not been detected in the analysis of the Patient and Family Participation in Nursing Care Scale. Furthermore whilst the hospital and community health professionals shared some common views, issues again varied, with community nurses perceiving their understanding of the concept to be greater than that of hospital workers. This section thus demonstrates the limitations of using structured tools to measure complex phenomena. As one participant said at interview when asked if there was anything else he would like to comment on in relation to the research:

> *"No, not really apart from the questionnaire, I really don't feel I can answer several of the ..... quite a lot of the questions simply because I don't think any of the columns sort of apply to some of the questions ..... mean there's more than one answer to it all and I don't really like to tick off, I mean for instance the question about, I can't remember now ..... um. ..... patients come into hospital to have a rest and be looked after, I mean obviously they do and they don't, I mean they do because I mean hospitals ..... you are actually caring and looking after somebody, but on the other hand they've got to, I mean carry on looking after themselves as well so I mean you can't really put disagree, agree or whatever so I think I left quite a lot of them blank."*
> (Paramedic: P20(E)p12)

Having detected a difference in the data between those obtained by structured questionnaire (Patient and Family Participation in Nursing Care Scale) and those by interviews, (extracts of initial interviews and exit interviews) the following section examines issues arising from the participant observation field notes accompanied by illustrative quotes from the exit interviews. In particular these data focus on how health professionals' views changed when confronted with the reality of putting lay participation into practice.

PERCEPTIONS IN REALITY: FINDINGS FROM THE PARTICIPANT OBSERVATION DATA AND EXIT INTERVIEWS

Whilst health professionals claimed to hold positive views towards lay participation in care there was a distinct lack of evidence of lay participation in care in practice. Issues from the field notes reveal that when participants were given the opportunity to change their practice, the concept was not actively supported. Lay participation in care was not found to be part of normal practice and a lack of professional understanding of the concept was demonstrated. In fact only a few isolated professionals viewed the concept as part of their normal working practice. Some serious doubts were

expressed about lay participation being part of health care practice. Health professionals feared a lack of positive response to lay participation in care from the public and expressed their own professional doubts and concerns. Furthermore health professionals were found to be lacking in the necessary skills in order to put lay participation in care into practice. Other issues less directly related to lay participation in care and more related to changing practice in general are also identified in the field notes and are discussed in the following chapter. A more detailed summary of the issues which arose from the field notes can be found in Appendix XXII.

Reluctance to practice lay participation in care

There are numerous examples in the field notes where despite a policy on lay participation in care having been agreed by the ward team, some professionals were reluctant to act upon it and in some cases actively contravened it. For instance, it was agreed that the house officers would discuss medical treatments with patients and encourage them to monitor their own drug taking using a medicine reminder card. However, as reported in the exit interviews the system was never implemented properly (Exit Interviews: N: 20%; M: 70%; P: 33%; J: 42%). It appears that the junior medics were not committed to filling out the medicine reminder cards for patients (Exit Interviews: N: 30%; M: 30%; P: 17%; J: 27%) and it was only at the end of their 3 month allocation that they realised the importance of the medicine reminder cards (Exit Interviews: N: 10%; M: 30%; P: 5%; J: 15%). For some medics the importance of involving patients in care (in this case a better understanding of their drug regimes) did not become apparent until they had gained some first hand experience of the effects of not so doing. As one medic said:

> *"I think it's a good idea I mean it reminds me I really should sit down and go over things with the patients because often in the heat of the moment you forget and I think it highlights, you know, having spoken to a few patients who've been in, been discharged and have come back in, you realise it's a big problem."*
> (Medic: M17(E)p12)

Interestingly, despite the lack of commitment to the medicine reminder card system in practice, in theory medics expressed positive attitudes. For medics and paramedics the medicine reminder card system was seen to have improved their awareness of the importance of drug education (Exit Interviews: N: 0%; M: 60%; P: 67%; J: 38%). Some medics commented that they had not realised how little patients knew about their drugs (Exit Interviews: N: 20%; M: 30%; P: 0%; J: 19%). Medics in particular thought that the medicine reminder card system was important and should

continue (Exit Interviews: N: 10%; M: 80%; P: 17%; J: 38%) and commented that they had received positive feedback from patients on the system (Exit Interviews: N: 10%; M: 60%; P: 17%; J: 31%) in that they viewed it as a useful prompt to take their drugs (Exit Interviews: N: 0%; M: 30%; P: 17%; J: 15%). As one medic said:

> *"I think the medicine reminder cards have been very important because I think it has focused everyone's attention on the crucial need to transfer to the patient knowledge about their drugs. And for the patient and the relatives to understand what they are for, what they look like, time of administration and to take on that responsibility."*
> (Medic: M2(E)p2)

However, in practice, the medics tended to view the medicine reminder cards as a low priority, claiming they were too busy to give them out (Exit Interviews: N: 10%; M: 30%; P: 0%; J: 15%). As one said:

> *"Because initially it requires more time. If you have to sit down with a patient or relative and explain things in a greater depth than you would normally, and teach them to do things, then the initial input takes a lot of time ..... it's very easy to say 'Oh well, we'll do it some other time' ..... You know you don't want to be difficult with them, it just wasn't practical at the time."*
> (Medic: M30(E)p8/9)

Other examples where lay participation in care was not actively supported in practice include patients being stopped from monitoring their own symptoms, lay people not being made to feel welcome on the ward, patients not being involved in discussions about themselves, conservatism stifling the uptake of lay ideas and the agreed policy on lay participation in care not being adhered to.

These findings support the conclusions arrived at whilst working on the ward as a participant observer.

Lack of evidence of lay participation in care

The exit interviews indicate that some participants felt lay participation in care was not part of normal practice (Exit Interviews: N:10%; M: 40%; P:50%; J: 31%). Similarly field notes recorded that lay participation in care was rarely mentioned in report and when discussed was only mentioned superficially. Staff did not appear to be aware of patients' family and friends and were unable to give relevant information about

patients' social circumstances in meetings. Furthermore lay participation in care was found to require complex skills such as listening, assessing, decision making, teaching and communicating but health professionals were found to lack confidence in such educative and supportive roles. For instance, opportunities for patient education were frequently missed and/or off loaded onto specialists. Communication with patients and their family and friends tended to be allocated to those with the least experience such as junior medics. Patients and their family and friends were sometimes ill prepared for discharge and where discharges were not properly planned this on occasion led to delays, complaints and readmissions. Professionals did not share with patients all the information available. For instance, patients did not have access to either their own medical notes or nursing care plans and there were times when families were informed of poor prognoses without the patients having been informed. There was no systematic way of professionals sharing with each other what patients and their family and friends knew about their conditions and any teaching was largely unplanned and poorly co-ordinated. Families and friends were not encouraged to be involved in care planning and tended only to be drawn into discussions immediately before discharge. With the exception of ward rounds there were no set times when professionals made themselves available to discuss patient care. But the formal nature of the ward rounds and the fact that they were often used as teaching sessions for other professionals inhibited lay people from being more involved in discussions. As one nurse remarked:

> *"I mean you see it all the time. I think if you go on a ward round the relatives will always leave the bedside and the doctors never encourage them to stay unless there's something particularly that they feel is relevant you know, how are you going to manage at home sort of thing, or a particular question they want to ask. But like they're quite happy for the relative to leave, you know, and on occasions when the relative has perhaps been a little more aggressive and not left, I've always perceived that some of the medical staff and the nursing staff have felt quite uncomfortable by the relative's presence."*
> (Nurse: N10(I)p1/2)

Another nurse commented:

> *"you know ..... often when we're turning people or doing a basic procedure we ask the patient's relatives to leave the room or leave the ward, I mean if the patient doesn't mind, why can't they stay there, I mean as long as we're doing things properly and there's nothing to hide why can't they stay and be there, I*

mean we tend to sort of like mysticise and I think ritualise a lot of things and leave the family and friends out of things and I just don't think that's necessary."
(Nurse: N11(I)p26)

There was little discussion amongst professionals concerning patients' worries or how families might be coping at home. Family and friends who acted as informal carers at home were not invited to be involved in care in hospital. Opportunities were missed where patients and their family and friends could have been more involved in care. On occasion it was actively discouraged. An extract from the field notes illustrates this point:

"An incident happened on the ward today which I felt particularly uncomfortable with. A patient who had been admitted with alcoholic liver disease and ascites and had a right sided cerebrovascular accident and left above the knee amputation in the past, had been sat out in his chair and at 3pm asked me to help him back to bed. I told him I couldn't manage him on my own and would get the help of another nurse. However, none of the nurses I asked were willing to help me. It appeared to have been generally decided that he was a lazy patient and wanted to lie on his bed too much. For this reason the nurses said he would have to sit out for longer. I went back to the patient and said there were no nurses available and I would help him back to bed later. Not long afterwards the nurses came out of their tea break and despite the patient's cries for help to be put back to bed, they continued to ignore him. I felt most uncomfortable with the situation but really unable to exert any power or influence. I'm not sure some of the nurses realise that participation in care could also be viewed as involvement in decision making as well."
(Field Notes: R(F)p68)

Where lay participation in care did occur it tended to be initiated by lay people rather than professionals. More frequently it involved AIDS patients and their family and friends. Health professionals claimed to be learning a lot from the way in which AIDS patients were forcing them to look differently at the way in which care was being given and lay participation in care was a major focus. As on nurse said at interview:

"I feel you've got to change because if you don't change you're not going to give the patients the care they want, and particularly, I mean I'm emphasising AIDS because it's like an epidemic at the moment, there's so many people who are going to ..... are demanding now to be so involved in their care and their families

to be involved in care, and their lovers and their friends, so if we don't respond to them and their needs, we may as well give up our job now because I just feel that, you know, if we just give our patient a bed bath and don't think about why we are doing it, you know, asking how they're feeling and how they're coping, we might as well just give up now because that's part of the patient."
(Nurse: N14(I)p16)

Whilst in general lay participation in care was not seen to be part of normal practice, the field notes recorded a few professionals (paramedics and district nurses) who considered it to be part of their general approach to care. District nurses were keen to talk about the involvement of lay people in care and the paramedics saw it as an opportunity for better teamwork. It was also claimed by the paramedics that the importance of multidisciplinary team work had been very much stressed in their education.

However, in general the field notes recorded a lack of evidence of lay participation in practice. Another theme identified in the field notes which supports this lack of evidence, is that health professionals were unfamiliar with the concept itself and lacked a proper understanding of it. This theme was also supported by the interview data.

Lay participation in care: a new way of thinking

Field notes recorded that professionals found it difficult to make positive suggestions as to how lay participation in care might be encouraged or implemented. Whilst collectively the initial interviews had given rise to many suggestions for change individually few ideas had emerged. Following the interviews participants would often comment that they had never really considered the subject before and for some it had made more sense when they were asked to reflect on their own personal experience of being in hospital and the extent to which they had been involved in their own or another's care. The majority of participants had some experience of either themselves or close family and friends being in hospital (Initial Interviews: N=83%; M=71%; P: 92%; J: 82%). Interestingly nurses and paramedics commented that during this experience lay participation in care had not been encouraged and that they would have been more involved if they had been invited (Initial Interviews: N=33%; M=14%; P: 46%; J: 31%). Nurses also complained about insufficient information being given to them by the health professionals caring for them (Initial Interviews: N=39%; M=21%; P: 8%; J: 24%) as well as feeling isolated (Initial Interviews: N=28%; M=0%; P: 15%; J: 16%). On the other hand medics felt they had been treated differently because they were a member of the health profession (Initial Interviews: N=6%; M=36%; P: 6%; J: 18%) and that there were some areas of care where they had been quite happy to be passive as patients (Initial

Interviews: N=0%; M=36%; P: 15%; J: 16%). The health professionals suggested that the interviews had been educational and had made them confront issues they had not thought about previously. As one medic said:

> *"No. ..... it's interesting, I'm glad you asked about, trying to put it on a personal thing, because you suddenly think of different aspects and how inadequate you feel when a patient is in hospital and they're being looked after and you feel very inadequate."*
> (Medic: M6(I)p23)

Not all professionals had been trained to think about patients holistically and felt they had come to appreciate the importance of lay participation in care through experience. As one junior medic commented:

> *"You think a good houseman (sic) just gets the tests done and gets the results and forgets about all the other things like, you know ..... I'll never forget, someone died, and it just didn't dawn on me to ring the relatives, you just don't think about those sort of things. I mean now I do, but when you first start, because as a student you have nothing to do with the social situation with the patient, it's all like ..... well they've got this or that, what does it mean. ..... you're thinking more about the clinical side of the patient rather than every other implication."*
> (Medic: M18(E)p6)

For many health professionals lay participation in care represents a new way of thinking and they require help to develop the understanding that it is an approach to care rather than a set of tasks to be implemented. The democratic principles of lay participation in care are quite challenging as health professionals appear to have a tendency to be prescriptive in advice and authoritarian in manner. It was found that some professionals found it hard to participate with each other let alone lay people. Nurses and medics claimed that lay participation in care had not been emphasised in their training and the medics in particular found the concept difficult to talk about, seeing it more as a nursing issue. The field notes recorded that in reality health professionals actually had some serious doubts about lay participation in care and believed they lacked the skills to practise it.

Doubts about lay participation in practice

The doubts held by health professionals centre around a concern that the public does not feel positive towards lay participation in care, that professional care is thought to be better and that there is a lack of suitable patients for lay participation in care.

Perceived lack of positive response from public

Several incidents recorded in the field notes seem to suggest that some members of the public feel less than positive about getting involved in care. When the patient letter was distributed (see Appendix VIII) inviting patients and their family and friends to be involved in care it really made very little impact and health professionals suspected that only a minority wanted to be more involved. It appeared that few people had regular visitors who were able to stay long enough to get more involved in care on the ward. Some patients were not interested in health promotion and did not want to know about lay support. One family felt very negative when invited to participate in care. They felt they were doing enough and resented the suggestion they might want to do more. As observed in the field notes recorded:

> *"The letters had been given out to patients over the weekend. One patient's relatives made an adverse comment when asked if she would like to participate. She said she loved her husband but did not want to nurse him. She felt he would not want her to do such things as empty his catheter bag and help wash him. This was a nurse's job and she would need help after discharge home. The patient is very keen to go home and it is unlikely that they will be given the degree of help needed to keep him at home without family participation. The nurses were surprised at this reaction because until this point the wife had been helping a lot on the ward."*
> (Field Notes: R(F)p330)

Other families saw hospitalisation as a form of respite care. For some involvement led to conflict between the patient and their significant other. For others, the health professionals' less authoritarian and more open approach to patients led families to feeling angry. For instance, one family thought the nurses should have been more assertive with a patient who refused to wash and another family were shocked when a nurse spoke openly to a patient about cancer. Such negative reactions from lay people to some degree probably influenced how health professionals viewed the concept of lay participation in care.

Professional doubts and concerns

Health professionals also expressed concern that lay people may make mistakes with technical aspects of care and would need to be closely monitored. They questioned what the legal implications would be if something went wrong. Lay care was not seen to be as good as professional care and many patients were seen to be unsuitable for involvement on account of mental impairment, being too dependent and having too many visitors. It was felt that some patients would not be interested in lay participation in care and would want to rely on an expert. It was felt that some patients might not benefit from lay participation in care. For instance, being more open and telling the truth was thought to be potentially dangerous for some patients with poor prognoses and participants questioned whether family participation might lead to loss of patient independence. Professionals felt guilty and worried that some people might view them as attempting to off load their jobs and responsibilities and felt that society tended to depend on the NHS rather than on families for support. Forming closer relationships with patients by viewing them holistically was thought to be more stressful for professionals and the need for extra support for them was identified. It was argued that some professionals did not want to develop educative and supportive roles because patient teaching was thought to be too time consuming and social care was not seen to be as important as medical care. It was suggested that health professionals might not know enough to give information to lay people and in particular noted that health professionals lacked skills to practice lay participation in care. On top of this it was felt that there was a lack of suitable patients for lay participation in care.

Perceived lack of suitable patients

Because lay participation in care was never properly offered on the ward, from the participants' perspective, it is difficult to say whether this was a real issue or a felt concern by the health professionals. Nonetheless it is an important issue in that it was still being expressed by half of the participants at exit interview. Of particular interest is that this view was held very strongly by paramedics (n=67%) who claimed to be more familiar with the concept of lay participation in care. It would be prudent to research this issue further. At exit interview the following comments were made:

> *"I don't see how you can start in any other way, when people are working from the starting point that they are working from.. People come in to be looked after and to be got better and the doctors are there to get them better, and that is how it operates ..... but the whole idea of getting people to take more responsibility for their own health and their own caring is a hard slog, isn't it? And that is what I*

was saying before, that how far will we ever progress because each time a new patient comes in, we are starting at the bottom again."
(Paramedic: P8(E)p7/8)

"Well, it's just the circumstances. Very often patients come onto the ward and leave as individuals. There haven't been relatives, they haven't been too close. Mrs L, to give an example, who is going home next week, who is better medically but probably can't live in a fourth floor flat on her own and manage. Well, relatives are worried about her but they could easily say, 'We can take her into our house until she gets better' - but they don't. So, if they don't what can you do? Some people don't have relatives - they just have friends in the distance and they can't participate in care. They're not prepared to give the full time that it takes."
(Medic: M31(E)p12)

"Well, I suppose deep down, I've always thought 'Yes, it's a good idea'. It's difficult remembering to give them out and I wasn't very good at it but now I think I am giving to just about every patient and it's rare that I forget. It's often difficult to actually - a lot of times you sit down with a patient and try to explain the drugs, just by how much you say and how long you stay there, you still have the uneasy feeling that it is going in one ear and out the other."
(Medic: M30(E)p3/4)

"I can only see it being practical to husband and wife or people actually living in the same house with the person, getting more involved. I mean a figure of about 10% was bandied about - it sounds to me fairly low but maybe it's realistic. It would be nice if it was higher. Again I keep saying that ideally it's a good idea but in practice, I don't know - you know, not that many people are available to really continue care outside hospitals, although you discharge most ..... the majority of patients go home - a lot do live on their own, although most have a spouse who it would be worth educating the patient's needs."
(Medic: M30(E)p6/7)

Participants questioned whether patients had any family and friends who could be involved in care in hospital. Whilst in the present study it was not possible to ascertain whether this was a real issue, it is interesting to note from Table 15 that of the six hundred and ninety admissions in a period of one year 67% were discharged home and only 38% were expected to return to hospital for an out patients appointment. Given that

the majority of illness is chronic and by definition not curable, it is likely that many patients go home on treatment, and are in need of further care and are unlikely to have further contact with the hospital. Therefore a case could be made for involving family and friends in hospital to offer the patient more support at home after discharge. Table 16 suggests that 85% had a next of kin of whom half was either a wife or a husband. Table 17 suggests that 55% lived in the same house as their next of kin.

Table 15: Details of patients on ward (1/8/1988 - 31/7/1989)

Details of Patients on Ward (1/8/1988-31/7/1989)	No. of People	% of People
Admissions	690	
Males	409	59
Females	281	41
Discharged home	449	67
Transfer to another institution	17	3
Transfer to another ward (22 places)	131	20
Died	57	9
Self-discharge	12	1
No details	24	3
Discharge home with out-patient appointment	261	38
	No. of Days	
Average length of stay	16 days	
Average age	60 years	

Table 16: Details of patients' next of kin on ward (1/8/1988 - 31/7/1989)

Details of Patients' Next of Kin on Ward (1/8/88-31/7/89)	No. of People	% of People
Next of Kin	586	85
No next of kin	49	7
No details	55	8
Wife	157	27
Husband	77	13
Son	58	10
Friend	57	10
Daughter	54	9
Mother	44	8
Sister	39	7
Brother	37	6
Niece	15	3
Father	14	2
Nephew	7	1
Aunt	3	<1
Social Worker	3	<1
Grandson	3	<1
Son-in-law	2	<1
Brother-in-law	2	<1
Granddaughter	2	<1
Cousin	2	<1
Uncle	2	<1
Sister-in-law	2	<1
Warden	2	<1
Solicitor	2	<1
Doctor	1	<1
Daughter-in-law	1	<1

Table 17: Home details of patients' next of kin on ward during study (1/8/1988 - 31/7/1989)

Home Details of Patients' Next of Kin on Ward (1/8/88-31/7/89)	No. of People	% of People
Admissions	690	
Next of Kin (known address)	602	
Address not given	88	
Next of Kin in England	577	96
Next of Kin in other UK. country	15	2
Next of Kin abroad	10	2
Next of Kin in London	518	86
Next of Kin out of London	84	14
Same address (N of K) as patient	331	55
Not same address (N of K)	271	45
Next of Kin in London (not live together)	187	31

One cannot be sure that, even had it been offered, lay people would have wanted to be more involved in care. However, data from Tables 16 and 17 suggest that many patients had close family and friends living either with them or in the area. Thus health professionals' assessment that there was a lack of suitable people for lay participation in care is open to question. It is argued that, if it had been offered as a free option, patients and their families and friends might have been more willing to participate in care.

It is possible that other issues obstructed lay participation in care being offered, for example, health professionals lacking the skills needed to offer it.

Lack of skills to practise lay participation in care

Several health professionals identified that they lacked the communication skills needed to offer lay participation in care as an option and felt they needed a role model to be able to put it into practice. Part of the problem seemed to be an inability to listen to patients, to help them to come to terms with their situations and to decide what was best for them as individuals. The field notes recounted an incident on the ward where a nurse recognised that she was too busy trying to do something for the patient rather than offering support to the patient:

> *"When I arrived on the ward N1 was having difficulties with one of her key patients - a gentleman with carcinoma of the spine about whom there had been a case conference. She was in the process of trying to arrange another meeting of the team to discuss further his desire to go home. She said that over the weekend he had become withdrawn, tearful and angry. His wife had not been in and she clearly did not want to participate in care. N1 was determined to get him home. I said I would go and talk to him and came back with a completely different*

picture. He said he had thought a lot over the weekend and now realised how impossible it would be to go home at the moment in realistic terms. His wife couldn't cope and it was unreasonable to expect her to. He had not really thought it through before and recognised that what he needed was basic care and the rest would have to be reviewed at a later date. He talked about having wasted people's time and I assured him our job was to help identify what he wanted out of life and present the options to the whole family.

When I discussed this with N1 she said she felt inexperienced and had not been asking the right questions. She hadn't herself thought it through and considered that it would take two nurses for both day and night shifts to cope with turning him. She had been focusing too much on the patient and what he wanted."
(Field Notes: R(F)p371)

Other professionals complained that they felt ill at ease talking to patients and lacked the appropriate teaching skills. They recognised that in the past they had tended to leave the teaching of patients to others. As one nurse said:

"I also find it very hard to teach people (relatives and friends) things. I feel, 'I should be doing this, I am the nurse, I know what to look for. Will the relatives be able to do it? Will I remember to tell them everything to look for if anything goes wrong - and they don't realise that they are doing something wrong and might endanger the patient's life. Am I teaching properly?' With the health education leaflet, for the first time, I was sitting down talking about their illness, what to look for, and I didn't realise how little they knew and how bad an educator I was. I never had to do it before. I've actually sat down and educated someone and I realised that I was quite bad at it. I couldn't put things across."
(Nurse: N1(E)p3)

Interestingly student nurses were thought, by the qualified nurses, to be better trained to discuss lay participation in care with patients. Qualified nurses struggled to know what questions to ask when trying to get a holistic perspective. Similarly medics suggested they were not taught to be holistic in their approach to care. Health professionals seemed to lack not only the skills to educate and support patients and their family and friends but also their own colleagues. They had difficulty assessing, planning and evaluating care for individuals and lacked the confidence in their management skills to work with colleagues changing general practice. One of the key problems the new charge nurse identified when she joined the ward team was that the staff urgently needed

professional development to build up their confidence and develop new ways of thinking. Without attention to these skills she believed lay participation in care could not be achieved.

Thus the field notes reveal that there was a distinct lack of evidence of lay participation in practice. The implementation of lay participation in care was not actively supported and was not found to be part of normal practice. Except for a few individuals, health professionals appeared to be unfamiliar with the concept and several had some doubts as to whether, in reality, it was a good idea. They perceived that the public did not want lay participation in care and similarly they had their own reservations about it being as good as professional care. Furthermore the health professionals felt inadequately prepared to practice lay participation in care, particularly in respect of the necessary skills, for example, exploring patients' preferences for involvement in care with them.

SUMMARY

This chapter has described the health professionals' perceptions of lay participation in care. It is interesting to note that whilst the results of the Patient and Family Participation in Nursing Care Scale indicate that health professionals hold positive attitudes towards lay participation in care, triangulation of these data with those from the interviews and field notes reveal that, when probed more deeply, some health professionals hold serious reservations about the concept and are reluctant to apply it to their health care practice. Health professionals do not appear to understand what is meant by lay participation in care and do not recognise it as part of their normal practice. Some health professionals question whether lay participation in care is wanted by the general public and doubt that its implementation would be successful on account of a lack of suitable patients. Others questioned whether lay care is as good as professional care and are therefore reluctant to pass over their control to non-professionals. Furthermore when lay participation in care was attempted, health professionals found they lacked the skills to enable such an approach to care.

Findings from this study show that what people say they feel in theory may be very different to how they actually feel and do in practice when confronted with an issue in reality.

Clearly the health professionals' perception of and attitude towards lay participation in care is likely to have influenced their behaviour in practice and may be one plausible explanation as to why the concept was never implemented properly in practice. However, other barriers to change have also been identified in the course of this

action research study and it is argued that these factors would influence negatively the outcome of any change project. These barriers to change are described in Chapter 8. The following chapter explores the changes which were achieved in the course of this action research study.

CHAPTER 7

CHANGES ACHIEVED IN PRACTICE

INTRODUCTION

This chapter describes the changes in health care practice achieved during the course of the study. As described in Chapter 5 data were collected using a variety of methods namely, questionnaires, interviews and field notes based on participant observation. Whilst change is extremely difficult to measure, the triangulation of data suggests that some positive changes did occur on the ward. Whilst participants felt frustrated that little seemed to have been achieved in terms of lay participation in care, there is evidence of some positive change. These changes include the development of more positive attitudes towards lay participation in care amongst professionals and improvements in ward organisation to facilitate lay participation in care. Given that lay participation in care is about a general approach to work, it could be claimed that these indicators of change show some success with the innovation under study. However, the question remains what more could have been achieved if the innovation had been supported for longer and if some of the difficulties of changing practice could have been addressed?

The unstructured approaches to assessing change included data from interviews and the field notes. Each of the data sets is examined in turn beginning with the more structured tools used in the study.

FINDINGS FROM THE STRUCTURED INSTRUMENTS USED TO ASSESS CHANGE

Three structured instruments, Ward Learning Environment Rating Scale (Fretwell, 1982), Nursing Process Measurement Scale (Brooking, 1986), and Qualpacs tool (Wandelt, 1976) were used to assess change over time. Analysis of the data from these instruments indicate improvements in the ward learning environment, the implementation of the nursing process and in the quality of care given over time.

Results of the ward learning environment rating scale

The Ward Learning Environment Rating Scale was used to assess the learning environment climate on the ward (see Appendix XIV). The questionnaire consists of nine sets of statements concerned with nurse training in the ward situation (see Chapter 5). As already explained in Chapter 5, the data were analysed using the statistical software

package SPSS-X and non-parametric hypothesis tests were used. Basic descriptive statistics were used to summarise the data and frequency distributions were then performed to look at the spread of the data. Following this each question was correlated against time using once more by means of the Spearman rank correlation coefficient. Scatter plots were used to look at each question over time. A detailed account of the findings can be found in Appendix XXIII.

Using the Spearman rank correlation coefficient to analyse these data, Table 18 summarises the frequency of responses to each question in relation to time. The table illustrates that Questions 1, 2, 4, 5, and 9 were all significantly correlated (at 5% level) in relation to time with Questions 2 and 9 being more highly significant at 1% level. All significant findings were found to be positively correlated. Examination of scatter plots indicate linear relationships between variables suggesting the ward learning environment improved over time. It should be noted that in general, correlations are low and there is some scatter.

Table 18: Ward Learning Environment Rating Scale - Spearman correlation coefficients (questions in relation to time)

Question	Time	Question	Time	Question	Time
Quest 1	.5004 N(17) SIG.020 *	Quest 2	.6408 N(17) SIG.003 *	Quest 3	.2371 N(17) SIG.180
Quest 4	.4302 N(17) SIG.042 *	Quest 5	.5750 N(16) SIG.010 *	Quest 6	.2621 N(17) SIG.155
Quest 7	-.2191 N(17) SIG.199	Quest 8	.3692 N(17) SIG.072	Quest 9	.6468 N(17) SIG.003 *

*: significant at the 5% level

It would appear therefore that over time the most significant changes ($p<0.01$) include the medics becoming more interested in teaching the nurses on the ward and the learners feeling that they had liked more working on the ward. Other significant changes over time ($p<0.05$) include the learners feeling that there was more to learn on the ward, and qualified nurses being seen to do more teaching.

It is interesting to note from an analysis of the qualitative comments to questions 10, 11 and 12 of the schedule (which asked learners to comment on how they had found working on the ward in relation to other wards) that the majority of negative comments tended to come from learners who had started work on the ward when the project had only been in progress for few months, whilst the more positive comments tended to be

made later in the project. The only comments which seemed to be made throughout the entire year was the suggestion that the patients on the ward were interesting to learn from and that staffing levels were inadequate which had led to poor supervision of learners. Table 19 and 20 summarise the negative and positive comments made in relation to time.

Table 19: Ward Learning Environment Rating Scale - negative comments on ward learning environment in relation to time

Negative Comments Made	A	S	O	N	D	J	F	M	A	M
Patient care poor - needs improvement (inconsistent)	3	1	1	1		1				1
Communication poor amongst team	2		2	2			1	1		
Poor teaching from qualified nurses	3		1	1		1				
Poor communication with patients	1	1		2		1				
Staffing levels inadequate - lack of supervision				1		3	1			
Lack of support and enthusiasm from staff		1	1	1		1				1
Care plans poorly done	1	2		1				1		
Care - task oriented	1		1	1			1			
Time wasted on ward	1									
Level of responsibility given - low		1								
Not able to work with own patients - hard to get to know						1				
Primary nursing and LPC not working								1		
Lack of notice for discharge										1

A-M: August - May

Table 20: Ward Learning Environment Rating Scale - positive comments on ward learning environment in relation to time

Positive Comments Made	A	S	O	N	D	J	F	M	A	M
Generally good patient care		1		3		2	1	2		1
Patients interesting - lot to learn	2	2		1		2		2		1
Good working atmosphere - staff helpful and friendly	1	1				2	1	1		
Students comments taken notice of						1				
Not so many dependent patients needing nurses time				1						
Care plans effective						1				
Encouraged to work in one area for period of time						1		1		

A-M: August - May

From this analysis there is evidence that the ward learning environment improved on the ward over time. Another area that appeared to improve over time was the practice of individualised patient care as data from the Nursing Process Measurement Scale revealed.

Results of the nursing process measurement scale

Another aspect of the ward practice that was influenced by the introduction of lay participation in care was the use of the nursing process on the ward. The nursing process

is a systematic problem solving approach to nursing care that places the patient at the centre of planning and evaluating care.

The Ward Nurses' Self Rating Scale was used to assess the implementation of the nursing process on the ward (see Appendix XV). It consists of thirty seven questions and can be divided into four subscales (see Chapter 5). The data were analysed using the statistical software package SPSS-X and non parametric hypothesis tests were used. Spearman rank correlation coefficient was also used in the analysis (see Chapter 5). A detailed account of the findings can be found in Appendix XXIV.

The frequency of responses to each question in relation to time are summarised in Table 21.

Table 21: Nursing Process Measurement Scale - Spearman correlation coefficients (questions in relation to time)

Question	Time	Question	Time	Question	Time
Quest 1	-.3953 N(31) SIG.014 *	**Quest 2**	-.2864 N(31) SIG .059	**Quest 3**	-.3673 N(31) .021 *
Quest 4	-.5948 N(31) SIG.000 *	**Quest 5**	-.6270 N(30) SIG.000 *	**Quest 6**	-.3537 N(31) SIG.025 *
Quest 7	-.2503 N(31) SIG.087	**Quest 8**	-.3711 N(30) SIG.022 *	**Quest 9**	-.5987 N(31) SIG.000 *
Quest 10	-.5713 N(31) SIG.000 *	**Quest 11**	-.4565 N(31) SIG.005 *	**Quest 12**	-.1714 N(31) SIG.178
Quest 13	-.4272 N(31) SIG.008 *	**Quest 14**	-.2283 N(31) SIG.108	**Quest 15**	-.2421 N(31) SIG.095
Quest 16	-.2364 N(30) *SIG.104*	**Quest 17**	-.1932 N(30) *SIG.153*	**Quest 18**	-.2953 N(31) *SIG.053*
Quest 19	-.3801 N(30) SIG.019 *	**Quest 20**	-.4751 N(30) SIG.004 *	**Quest 21**	-.3372 N(30) SIG.034 *
Quest 22	-.0983 N(31) SIG.299	**Quest 23**	-.5969 N(31) SIG.000 *	**Quest 24**	-.6236 N(30) SIG.000 *
Quest 25	-.4465 N(30) SIG.007 *	**Quest 26**	.3380 N(30) SIG.034 *	**Quest 27**	-.5115 N(29) SIG.002 *
Quest 28	-.6496 N(29) SIG.000 *	**Quest 29**	-.5671 N(27) SIG.001 *	**Quest 30**	-.4281 N(30) SIG.009 *
Quest 31	-.2620 N(23) SIG.114	**Quest 32**	-.4901 N(29) SIG.003 *	**Quest 33**	-.4025 N(30) SIG.014 *

Table 21: Continued

Question	Time	Question	Time	Question	Time
Quest 34	-.3220 N(30) SIG.041 *	Quest 35	.0277 N(29) SIG.443	Quest 36	-.1101 N(29) SIG.285
Quest 37	-.1912 N(30) SIG.156				

It can be seen that answers to questions 1, 3, 4, 5, 6, 8, 9, 10, 11, 13, 19, 20, 21, 23, 24, 25, 26, 27, 28, 29, 30, 32, 33 and 34 have all significantly correlated (at 5% level) in relation to time. Answers to questions 4, 5, 9, 10, 11, 13, 20, 23, 24, 25, 27, 28, 29, 30 and 32 are more significantly correlated at 1% level. All significant findings are found to be negatively correlated with the exception of Question 26. Examination of scatter plots indicate linear relationships between variables suggesting that over time the nursing process scores did improve on the ward. It should be noted that in general, correlations are low and there is some scatter. However, there is a link between an improvement in the ward learning environment and time.

It would appear that the most significant changes ($P<0.01$) occur in the Evaluation Subscale (four out of six questions) followed by the Implementation Subscale (five out of ten questions), and the Planning Subscale (four out of nine questions). There is also some significant change ($p<0.05$) in the assessment scale (six out of eight questions). The only questions where there are no significant changes ($p>0.05$) include Question 2, 7, 12, 14, 15, 16, 17, 18, 22, 31, 35, 36 and 37. This lack of significant change tends to occur in the Planning Subscale (five out of nine questions) and in the General Subscale (three out of four questions). The inconsistency in findings for the Planning Subscale suggest that whilst there are some significant improvements in care planning over time, this does not involve improvements in goal setting.

Because five people only chose to make comment, the qualitative comments over time were not analysed. However, it is possible to examine whether the qualified nurses saw different changes to the learner nurses over time. Table 22 summarises the correlation coefficients in relation to time for each subgroup (qualified nurses and learner nurses).

Table 22: Nursing Process Measurement Scale - Spearman correlation coefficients (questions in relation to time) for qualified nurses and learner nurses

Question	Qualified Nurses Time	Learner Nurses Time	Question	Qualified Nurses Time	Learner Nurses Time
Quest 1	-.6862 N(13) SIG.005*	-.1186 N(18) SIG.320	Quest 2	-.2994 N(13) SIG.160	-.2480 N(18) SIG.168
Quest 3	-.3372 N(13) SIG.130	-.1562 N(18) SIG.268	Quest 4	-.6786 N(13) SIG.005*	-.5346 N(18) SIG.011*
Quest 5	-.7531 N(12) SIG.002*	-.5793 N(18) SIG.006*	Quest 6	-.5251 N(13) SIG.033*	-.1327 N(18) SIG.300
Quest 7	-.3286 N(13) SIG.136	-.2514 N(18) SIG.157	Quest 8	-.5976 N(12) SIG.020*	-.2762 N(18) SIG.134
Quest 9	-.3241 N(13) SIG.140	-.6457 N(18) SIG.002*	Quest 10	-.4937 N(13) SIG.043*	-.5129 N(18) SIG.015*
Quest 11	-.6272 N(13) SIG.011*	-.5132 N(18) SIG.015*	Quest 12	-.2994 N(13) SIG.160	-.2890 N(18) SIG.122
Quest 13	-.3483 N(13) SIG.122	-.5130 N(18) SIG.015*	Quest 14	.0151 N(13) SIG.480	-.3263 N(18) SIG.093
Quest 15	-.6087 N(13) SIG.014*	-.0505 N(18) SIG.421	Quest 16	-.2857 N(13) SIG.170	-.1273 N(17) SIG.313
Quest 17	-.2875 N(13) SIG.170	.0528 N(17) SIG.420	Quest 18	-.4626 N(13) SIG.056	-.1659 N(18) SIG.255
Quest 19	-.7506 N(13) SIG.002*	-.1838 N(17) SIG.240	Quest 20	-.6405 N(12) SIG.012*	-.4053 N(18) SIG.048*
Quest 21	-.4206 N(12) SIG.087	-.3533 N(18) SIG.075	Quest 22	-.4028 N(13) SIG.086	.0979 N(18) SIG.350
Quest 23	-.4711 N(13) SIG.052	-.6439 N(18) SIG.002*	Quest 24	-.6071 N(12) SIG.018*	-.5424 N(18) SIG.010*
Quest 25	-.6469 N(12) SIG.012*	-.3464 N(18) SIG.080	Quest 26	-.0739 N(12) SIG.410	.3317 N(18) SIG.089
Quest 27	-.7931 N(11) SIG.002*	-.4143 N(18) SIG.044*	Quest 28	-.7931 N(11) SIG.002*	-.6193 N(18) SIG.003*
Quest 29	-.4031 N(10) SIG.124	-.5131 N(17) SIG.018*	Quest 30	-.5128 N(12) SIG.044*	-.2172 N(18) SIG.193
Quest 31	-.7071 N(8) SIG.025*	.0545 N(15) SIG.423	Quest 32	-.8224 N(12) SIG.001*	-.3412 N(17) SIG.090
Quest 33	-.6938 N(12) SIG.006*	-.3748 N(18) SIG.063	Quest 34	-.4736 N(12) SIG.060	-.3129 N(18) SIG.103

Table 22: Continued

Question	Qualified Nurses Time	Learner Nurses Time	Question	Qualified Nurses Time	Learner Nurses Time
Quest 35	-.1209 N(11) SIG.362	No Correlation	Quest 36	-.2060 N(11) SIG.272	-.0509 N(18) SIG.421
Quest 37	-.7284 N(12) SIG.004*	-.1004 N(18) SIG.346			

Table 22 shows the difference between qualified and learner nurses in relation to their responses to assessing the nursing process on the ward over time. It is interesting to note that they are only in agreement that there had been significant positive change on eight out of twenty three occasions (Questions 4, 5, 10, 11, 20, 24, 27 and 28). Improvements are not clustered in any one subscale but represent isolated questions from the Assessment, Planning, Implementation and Evaluation Subscales. Overall the qualified nurses perceive more significant changes over time than the learner nurses. Qualified nurses thought there had been improvements in relation to eleven questions which the learner nurses do not identify, compared with four questions which the learner nurses identify without agreement from the qualified nurses.

Thus it appears that significant change did occur on the ward both in relation to the ward learning environment and the nursing process. Positive change is also reflected in the findings from the quality assurance measure, Qualpacs.

Results of the Qualpacs assessments

Qualpacs (Wandelt and Ager, 1976) was used to measure the quality of care given on the ward. Nurse researchers working in the hospital made the Qualpacs assessments at the beginning (19/9/88) and end of the study (2/5/89).

The Qualpacs is a sixty eight question scale for measuring the quality of care received by patients either from direct nurse-patient interactions or from interventions on behalf of the patient (see Chapter 5). The scale is concerned with six areas of care including care received directed toward meeting psycho-social needs of the patient as an individual and as a member of a group, care received meeting physical needs, care received meeting both psycho-social and physical needs together, and care associated with dealing with communication and also with dealing with professional responsibility.

This rating scale allows for a possible range of scores: best (score 5), between (score 4), average care (score 3), between (score 2), and poorest care (score 1). The expected norm is "best care" for one or all the patients.

The findings from the quality assurance measurements should be viewed with caution because they depend on the assessment of care being given in a restricted area of the ward on two isolated occasions. The scores for each of the six areas of care at the beginning and at the end of the study are shown in Table 23.

Table 23: Qualpacs scores at beginning and end of project

Qualpacs Sub sections	Scores Beginning 19/9/88	Scores End 2/5/89
1. Psycho-social care - individual	2.2	2.6
2. Psycho-social care - member of a group	No recordings	2.1
3. Physical care	2.1	2.6
4. General	2.1	1.9
5. Communication	1.4	1.7
6. Professional implications	1.6	1.5
Overall Score	**1.9**	**2.1**

Whilst the findings from the Qualpacs score do not indicate that high quality care was being given on the ward (between average care and poor care), nonetheless findings suggest that some improvement in the quality of care did occur over time. These findings support other indicators of positive change over time (Ward Learning Environment Rating Scale and the Nursing Process Measurement Scale). It should be noted that the second Qualpacs measurement was taken in May during the "Transition Period: April-June 1989" (see Chapter 1). The original charge nurse had resigned and an acting charge nurse was in post. There was a sense of the ward being "held over" until the arrival of the new charge nurse. It is possible that the second score may have been higher if it had been taken immediately before the Transition Period.

FINDINGS FROM THE UNSTRUCTURED APPROACHES USED TO ASSESS CHANGE

This section begins by reporting on data from the initial interviews which summarised the changes health professionals wanted to make on the ward to facilitate lay participation in care. Following this, data from the field notes and exit interviews are used to examine the extent to which change was achieved.

Perceived changes needed

At initial interview participants were asked to comment on what changes they would like to see made on the ward to facilitate lay participation in care. These proposed changes were used to develop a ward policy on lay participation in care (see Appendix III). Whilst individually participants found it difficult to articulate what changes they wanted to make on the ward, collectively several ideas were proposed. The ideas expressed by more than 25% of any one group of health professionals are summarised in Table 24.

Whilst all groups of health professionals agreed on several changes, different groups emphasised different aspects (see Table 24). For instance, all groups recognised the need to make themselves more available to lay people and to encourage lay people to get involved in basic nursing care. However, whilst nurses and paramedics identified the need to develop their teaching roles (through educating, informing and supporting), medics particularly commented on the need to humanise care more by letting lay people know more about what was happening. Whether this indicates a difference in understanding about patient education (with medics seeing it as being more about information giving), is open to question and may be worthy of further research. It appears that compared with the medics, paramedics and nurses were more concerned about the way in which the ward would be organised to facilitate lay participation in care. Paramedics and nurses stressed the need to individualise care and proposed that the way in which the ward was organised should be changed to facilitate this. Paramedics also stressed the need for regular multidisciplinary team meetings and clear demarcation of roles and responsibilities.

From the initial interviews it is apparent that the ward was not organised in a way that was conducive to lay participation in care. As one nurse said:

> *"I don't feel that I know the patients' relatives and their backgrounds very well because I don't have time to sit down and talk to them for an hour and find out what all their problems are. But I think if primary nursing, or like where I looked after a certain amount of patients from the beginning to the end, I would get more involved and be more interested but when I know OK I'm that side today and I'm looking after someone else tomorrow. There's a limit to, you know, how many hours you can spend with each one of them."*
> (Nurse: N5(I)p18)

Table 24: Proposed changes to facilitate lay participation in care - main themes from initial interview data

Proposed Changes to Facilitate Lay Participation in Care	M %	P %	N %	J %
Emphasise teaching role				
Explain, educate, inform, support	21	46	56	42
Become more available				
Build up contact with relatives - more approachable	36	46	28	36
Take more time to talk - re-order priorities	14	38	6	18
Involve lay people in basic nursing care				
Involve in bathing, washing and dressing	36	31	33	33
Involve in lifting, transferring and mobilising	7	31	22	20
Make comfortable in bed			28	11
Create atmosphere conducive to participation				
Offer autonomy, privacy and respect	7	31		11
Make clear - part of team and can get involved	29	23	28	27
Monitor and check up				
Closely monitor and check up - after discharge	29	31	33	31
Improve communication - humanise care				
Improve communication - know what is happening	64	15	17	31
Ensure good multidisciplinary team work				
Have regular meetings	21	46	22	29
Offer participation in care as a free option				
Feel able to withdraw - not forced	29	15	33	31
Involve in care planning				
Discuss plan of care with patient and relative	14	23	39	27
Individualise care				
Tailor participation for individual	7		56	24
Assess desire and ability for involvement in care	29	46		22
Provide adequate facilities and resources				
Good facilities - somewhere to stay (quiet room)	21	38	11	22
Change organisation of ward				
Different system of nursing e.g. Primary Nursing	7	8	44	22
Key workers to co-ordinate and liaise with families		38	6	13
Offer clear guidelines and explanations				
Roles need to be defined and demarked	7	38		13
Involve in monitoring condition				
Involve in doing observations e.g. BP, F/B, stools, weight, urine	29		28	20
Introduce change sensitively				
Slowly educate - less threatening	7	8	28	16
Involve in treatment				
Self medication	14		28	16
Assist with medications - monitor pain control	29	8		11

M=Medics (14), P=Paramedics (13), N=Nurses (18), J=Joint (45)

Thus early in the study it became apparent that before lay participation in care could be introduced to the ward, more fundamental issues relating to ward practice needed to be addressed. Therefore, through regular multidisciplinary team meetings it was decided to introduce a modified form of Primary Nursing (Key Nursing) to enable named nurses to take responsibility for co-ordinating the care of individual patients. In this way it was thought that lay participation in care would have more chance of flourishing. To this end ward policies on key nursing (Appendix IV) and lay

participation in care (Appendix III) were agreed by the multidisciplinary team after much discussion and debate. Given that in an action research study, change is determined by the participants, it is not unusual for a project to take an unexpected direction. Thus in assessing change, this factor should be taken into account and changes, other than those originally intended, should be examined. These changes were largely examined using unstructured methods including the interviews and participant observation field notes. The following section now explores these data.

Positive changes achieved

Data on changes achieved in reality were generated by the exit interviews (refer to Appendix XX) and by keeping field notes (refer to Appendix XXII). By focusing on the process as well as the outcome, data from these helped contribute to a better understanding of what happened in reality as well as highlighting the success achieved.

It is noteworthy that for some, it was not until they had left the ward that they realised that they had changed in their approach to patient care and learnt something as a result of the project. As one nurse said:

N *"I'd just had enough of everything on the ward ..... internal conflicts going on, etc. But apart from that, I really enjoyed my time there and looking back, I think I learned a hell of a lot, that at the time I didn't realise - in terms of management and in terms of thinking about the patient and their relatives as a whole and trying to inform them and educate them better."*

R *"That's interesting that you say you realise that now rather than at the time."*

N *"Well, I mean ..... I knew. ..... every time you came up with new ideas, I thought 'Oh yes, that is really good' but I used to try to put them into practice but until I moved to another ward, I didn't realise how much I had learnt from Ward X. Whereas moving to another ward and now being able to come out at meetings and things with something that we had discussed on Ward X ..... then you suddenly realise that we did actually go quite a long way towards helping our patients more"*

(Nurse: N5(E)p21)

At exit interview participants were asked to describe the changes that had occurred on the ward as a result of trying to introduce lay participation in care that were

seen to be working. The changes identified by more than 25% of any one group are summarised in Table 25.

Table 25: Changes on ward that are working and good idea - exit interviews

Changes on Ward that are Working and Good Idea	N %	M %	P %	J %
More positive attitudes to LPC				
Increased awareness of need for LPC	50	80	50	62
Improved Multidisciplinary teamwork				
Improved MDT communication	60	30	100	58
Meetings - better informed and evidence of more thinking	30	20	33	27
Team pulling together more - better care	10	20	33	19
People know who to relate to in team better	40			15
Meetings good to discuss improvements in care			33	8
Improved patient education				
MRC introduced - better informed on drugs	30	70	50	50
Information leaflets - helpful and fun for patients	40	10	17	23
Better at teaching - health education	40	10		19
Information leaflets being used on ward		20	33	15
Better communication with relatives and friends				
Improved communication with relatives and patients	60	20	50	42
Patient letter good idea		20	33	15
Better understanding of patients and relatives				
Patients being seen holistically	50	10	33	31
Think about relatives more	50	10	17	27
Key nurse system - know patients in more detail	30	10	50	27
Key nurse system better way of organising care				
Better relationships within nursing team	40			15
See patients more holistically	40			15
Ward better organised	30			12
Good idea	30			12

Data from the field notes confirm several of the issues raised in the exit interviews and Table 26 summarises the main themes from field notes in relation to positive changes in practice.

Table 26: Positive changes in practice - main themes from field notes

Changing attitudes *
Better awareness of patients and their family and friends *
Patient education being viewed more positively *
Multidisciplinary team working together *
Ward better organised *
Change in ward charge nurse viewed positively *
Qualitative difference in charge nurses - key to change *
Lay participation in care in practice
Staff more confident with skills for lay participation in care
Participants willing to co-operate with research ideas in theory
Ownership of change - ward leaders facilitating change
Staff initiating own ideas
Ward learning environment improved for students
Creating a talking culture
Ward's reputation improving

* issues raised in exit interviews confirmed by field notes

The field notes provide confirmation of the data collected at the exit interviews in that the multidisciplinary team appear to be more positive towards the concept of lay participation in care, showing more awareness of patients and their family and friends and being more committed to patient education. Furthermore the field notes confirm that, as time went by, the health professionals were working closer together and were also better organised. Both data sets reveal that the change in ward leadership towards the end of the project was, in general, viewed positively and that the qualitative difference in leadership seen to be an important factor in facilitating change.

However, the field notes also show other positive changes in practice. First, there is some evidence of lay participation in care starting to be put into practice, with staff gaining confidence in the skills required to offer this approach to care. Second, the health professionals, having been reluctant to own the project ideas initially, started to demonstrate more initiative in facilitating change and be more willing to co-operate with the research. Third, a more democratic atmosphere was created on the ward, with the participants feeling better able to talk to each other about their thoughts, feelings and ideas. Finally the ward's reputation within the hospital was seen to be improving, in particular, by staff and students in the school of nursing.

The following section discusses each of these issues in turn.

Improved attitudes towards lay participation in care

At exit interview health professionals suggested quite strongly that their attitudes towards lay participation in care had become more positive as a result of being involved in the project. Most of the medics and half of the nurses and paramedics claimed to have developed a better awareness of the need for lay participation in care. The point is illustrated by the following two comments made by nurses and the last comment made by a medic:

> *"We did at least begin to change our way of thinking and to think deeper about what we were doing for the patients and their families and what could be done and just what was available to us, which I think a lot of us wouldn't have known really."*
> (Nurse: N5(E)p10)

"I think the nurses are now thinking a lot more of what is available in terms of support - counselling for the families - it's given more avenues in which they can go through. I definitely think of friends and families more than I ever did. I didn't realise that it was important that they were involved as well. So I think the education of friends and families has improved and discharge has improved."
(Nurse: N1(E)p2)

"I think one of the main values - and it may seem an odd thing to say - it has brought home to me how little often the nurses and the relatives understand what we are doing. In other words, part of it has been educational for me in demonstrating what a huge gulf there is, in terms of understanding what we are trying to achieve, as well as between us, the nurses and the relatives ..... and the patient, who clearly half the time hasn't a clue what we are doing. So I think that is the first thing - educational for me."
(Medic: M23(E)p3)

An improved attitude towards lay participation in care is a theme supported by the field notes. Over time some participants began to realise that it could not be introduced as a set of tasks but rather as a change in approach to care, requiring new ways of thinking. As one nurse reflected during a meeting:

"It was decided to discuss the patient with cancer of the spine, about whom there had been a case conference. X (staff nurse) recounted to those who attended that she had not got to know the family well enough and had not considered all the angles. She felt she had been too patient centred. This was reinforced by the others (4 staff nurses) who similarly said they didn't know the patient's family well enough to properly consider their participation in care either. X (staff nurse) also felt that she hadn't asked the right questions and it was only when I started to ask questions like 'How could the wife manage at night time?' that it seemed to make more sense. She felt it was really a question of attitude and she was going to have to learn a new way to think about and approach patients. It wasn't going to be a case of giving out a letter, much more would have to change. She felt she had learnt a lot from the experience. The meeting was brief but seemed to have identified some important issues."
(Field Notes: R(F)p373)

There was also some evidence of health professionals recognising the need for change and understanding that it would take time to change practice. Having been initially reluctant to change practice, as time went on, participants became more positive.

Gradually staff appeared to become more aware of the individual needs of patients and their family and friends. This was reflected in the nurses' handover report at lunch time which became longer as staff took more time to discuss patients in more detail taking account of their social situations. As the field notes reported:

> *"I went into the hospital to sit in on the lunch time report X (staff nurse) was in charge. Throughout the report she added information on aspects of patient care and showed a sound knowledge of her patients. X (another staff nurse) also added many comments and asked questions of the learners - something I had not noticed her do in the past."*
> (Field Notes: R(F)p528)

However, these changes in report were not always appreciated by the original charge nurse:

> *"I went onto the ward and sat in on report. The CNM had said she was going to come to the staff nurse meeting, so charge nurse wanted report to finish quickly. She said, 'Just give brief details, I'm sick of listening to all the waffle that has been going on for the last 6 months.' I wondered if this was a comment on the use of report to pass on more information. The reports were now indeed more informative than when I first began on the ward. Attempts were now made to give a problem oriented report and staff nurses often added their comments and sometimes learners were asked questions to check their understanding. It seemed a shame that she didn't appreciate this change and saw it merely as time consuming."*
> (Field Notes: R(F)p377)

The exit interviews also suggest that nurses and paramedics believe there was better communication between patients and their family and friends, although in the field notes this was not identified as an issue. Patients were considered from a more holistic perspective and both paramedics and nurses suggested that since the introduction of the Key Nurse System, patients and their social situations were becoming known in more detail. This greater awareness of patients and their family and friends was probably responsible for the general improvement in patient education on the ward.

Improved patient education

The exit interviews reveal that the medics thought that since the introduction of the medicine reminder system, patients had become better informed about their drugs whilst the nurses felt that there was now more health education on the ward. Whilst the

evaluation of the Medicine Reminder Card System had not been successful, some medics reported positive changes which they had identified in some patients returning to clinic after discharge. As one medic claimed:

> *" ..... but there are a few patients I have noticed coming back to clinic who are perhaps more informed about their drugs, than they might have been. Just one or two .... than they might have been before ..... Well, the one that sprung to mind is a chap called X who came in with an infarct and had loads of complications - heart failure, arrhythmias, stroke, and he got out and he had a very frail wife and he came back with his medicine reminder card and seemed to actually know the names of the drugs and what he was taking, and almost why, which, considering he is not the sort of patient you would normally expect that from, is probably an achievement in itself."*
> (Medic: M27(E)p5)

The field notes report similar findings:

> *"I turned to X (medic) who had been so busy recently that he had been unable to give out the Medicine Reminder Cards and asked if he wanted to make a comment. He said that recently he had made more time to give them out and had discovered their benefit. In particular a patient who had got hypertension and had been discharged home on drugs, had returned to an outpatients' appointment fully informed of his treatment which had been of immense benefit, not only to the patient, but to the doctor's management of the case. Records were not always available which indicated treatment at discharge."*
> (Field Notes: R(F)p664/665)

Interestingly whilst the majority of medics stated, at exit interview, that the Medicine Reminder System had led to the improvement of patient education, they also suggested that it was one of the changes that was not working properly (Exit Interviews: N: 20%; M: 60%; P: 33%; J: 38%). This inconsistency in the data may reflect that this was the medics' main focus in the project and that whilst improvements had been made, there was room for further improvement.

However, following the appointment of the new charge nurse, health education was viewed more positively by the multidisciplinary team and care was organised in such a way that the nurses were more able to be involved in patient education. For example as one nurse pointed out:

"X (new charge nurse) said that she was interested in letting patients be responsible for their own medications. Some of the HIV patients were being allowed to give their own drugs but this was unofficial. She felt conscious that taking the tablets away from patients on admission was stripping them of their individuality and self control, but she worried about issues of responsibility and accountability plus the threat of disciplinary action. I said I would get her some references on self administration, so that she could explore what others had done. At least the staff nurses were giving out their own drugs in their own areas now. Some staff nurses were responding well to this opportunity to get involved in patient education about treatments."
(Field Notes: R(F)p726)

Improved multidisciplinary teamwork

Whilst the improvement in multidisciplinary teamwork was not particularly recognised by the medics, it was seen to be of importance to non medics who valued the improved communication between professionals. As one paramedic said:

"I found on the ward, even though there were a lot of communication problems on the ward, people were aware of what was going on, and you could at least talk about things on the ward. I found most of the staff, nursing staff, were quite good and of any of the wards, I felt I got to know them. I mean, they knew you by name. And I don't know whether that was because of lay participation but I found them a lot easier to approach, much more than on other wards."
(Paramedic: P19(E)p12)

It was the nurses, in particular, who were seen to be communicating better within the team. As one medic said:

"Very, very slowly, I think communication is getting better. It takes a long time, but there's still an improvement. ..... I'm not just saying it, I actually do think it's improving. ..... things are getting done ..... people know what is going on, in general. There seems to be better communication now between doctors and nurses."
(Medic: M18(E)p8)

The field notes suggest that the multidisciplinary team meetings were much valued by all attending. They allowed ward issues to be discussed and plans to be made as to how the team might work better together. Paramedics said that they felt much more welcome on the ward and the communication became much less hierarchical. For

instance, over time, medics became less territorial and were willing to consider that alternative therapists (for example, aromatherapists) could have a role to play on the ward. There was a better team spirit, with medics communicating more directly to relevant staff about individual patients. This is illustrated in the field notes when the new charge nurse recounted a meeting with one of the consultants:

> *"X (new charge nurse) told me that recently X (consultant) had asked to see her about the ward organisation ..... He began by saying how pleased he was with the way the ward was organised. In particular he felt the nurses knew far more about their patients and contributed in a more meaningful way on the ward rounds. He said that it had taken some getting used to, as the ward round had to be divided up into areas and he had to accept the different inputs at different stages. He felt the atmosphere on the ward was noticeably better on the ward in recent months. X (new charge nurse) said the conversation was really constructive as she had the opportunity to talk about doctor-nurse relations. She felt able to point out that she didn't feel there was equality in the relationship and discussed how nurses seemed to have little input on hospital policy committees, being medically dominated. X (consultant) said he had never really seen things that way before and didn't appear to reject what she was saying. X (new charge nurse) found it helpful to talk about these things."*
> (Field Notes: R(F)p821)

Interestingly whilst paramedics had suggested unanimously that there had been improvement in multidisciplinary teamwork, they also saw this as being the area where change was least working. They focused on the fact that the multidisciplinary communication sheets were not being used properly (Exit Interviews: N: 10%; M: 30%; P: 67%; J: 31%). Again this may reflect the biggest area of concern for paramedics and in spite of some progress, it was thought that improvements could still be made.

Improved ward organisation

Turning to the matter of ward organisation and its impact on lay participation in care, at the exit interview, the nurses in particular suggested that the Key Nurse System was a better way of organising care on the ward and had led to better relationships within the nursing team. The strength of their commitment to this new system of delivering care can be seen in the following quote:

> *N "Overall, I just think that Primary Nursing has changed my idea of nursing completely. I think I would always like to work with that idea."*

R *"Really?"*

N *"Yes. After working like this for three or four months, I don't think I could go back to doing it the way we did it before."*
(Nurse: N8(E)p10)

One medic similarly spoke positively about the changes in the organisation of nursing care:

"Well I think there has been quite a few changes. I mean, I think the alterations in the nursing staff of having nurses who are specifically responsible for a patient, who have a good deal more knowledge about them and have contact with the relatives; who can talk much more knowledgeably to the medical staff about the patient; and then perhaps with that knowledge, transfer it increasingly to the patient and the relatives. I mean this has been a change."
(Medic: M2(E)p2)

The field notes likewise indicate that the ward had become better organised to facilitate lay participation in care, especially after the appointment of the new charge nurse. There was certainly a movement towards individualised patient care. The new charge nurse wrote the "off duty" in such a way as to try and ensure continuity of care. She introduced the Key Nurse System systematically with staff nurses being given the total care of a small group of patients and individual responsibility for a geographical area. She attempted to redirect thinking from task orientation to patient centred care. For instance, the patients' day was restructured so that patients would not be woken as early as 6am to take their first drugs of the day. To replace the routine drug round, each key nurse was given the responsibility for ensuring their own patients were given their drugs as prescribed. Care was decentralised and the lunch time handover between nurses became more detailed. This included involving the patients at the bedside. The standard of documentation became more individualised and better written. The nurses started to think more about nursing and getting closer to patients thus being better able to anticipate problems and needs. All this became possible under the guidance of the new charge nurse. However, in spite of the staff nurses commitment to the new changes on the ward, some staff did not find the transition easy and the new charge nurse found it difficult to stimulate them to examine and improve their practice. This rather irritated a new staff nurse who joined the ward and commented:

"Whilst I was waiting for X (new charge nurse) to finish her work on the ward, I sat in the office where Y (new member of staff) was having coffee. Y made an

interesting comment about the staff on the ward. She said that she was irritated by the way they all kept referring to the original charge nurse in a bad light. She questioned why they hadn't taken more opportunity to change and improve things now that the new charge nurse encouraged them to do this. She wondered if the original charge nurse was being scapegoated. Perhaps the staff nurses themselves were not capable of change."
(Field Notes: R(F)p800)

Once again it is interesting to note that whilst half the paramedics suggested the Key Nurse System had led to patients being known better, it was also suggested that this system was not being carried out properly (Exit Interviews: N: 10%; M: 20%; P: 50%; J: 23%). In the same way as patient education about drugs was the main concern of medics, it appears that as well as the emphasis on multidisciplinary team work, paramedics were also very interested in the organisation of ward work to facilitate lay participation in care.

Such inconsistencies may be the result of data having been gathered during the on-going process of change or, as suggested, may indicate that these were the areas of particular interest and concern for different groups of health professionals. It could also be argued that the nurses were particularly concerned about the key role the charge nurse played in relation to blocking or achieving change. From the nurses' perspective the newly appointed charge nurse had a positive impact in relation to change on the ward.

Positive impact of newly appointed charge nurse

At exit interview the nurses commented extensively on the difference that had been made on appointment of a new charge nurse. The difference in leadership style between the original and new charge nurses indicated that this issue was indeed a key variable in the change process. Table 27 identifies those characteristics in respect of ward management, raised by more than 25% of any one group seen to facilitate lay participation in care.

The difference in leadership style between the two charge nurses was also raised as an issue and recorded in the field notes (refer Appendix XXII). The original charge nurse was perceived as authoritarian, whilst the new charge nurse was seen to be more progressive as a professional leader and innovator of change. As one nurse pointed out:

"I think she (original charge nurse) like ..... the way she delivered her care was such a way that she told the patient what she was going to do and did it. I don't think I ever heard her asking the patients about their own care - or the relatives. She was quite authoritarian in her attitude towards staff. I don't think in the four

years that I worked with her that she ever consulted me on any aspect of any patient's care. I think she always told me, either what she wanted or told me what to do and I think that is the way I saw her react with all other members of staff that I worked with in that time as well.""
(Nurse: N10(E)p7)

Table 27: Difference in leadership style between original and new charge nurse - main themes from exit interviews

Difference in leadership style between original and new charge nurse	N %	M %	P %	J %
Better able to motivate staff - enjoy work more	90			35
More enthusiastic and interested	50	30		31
More interested in developing practice	50	30		31
Creates a better atmosphere and team spirit	50	30		31
More open to changing practice and adoption of other ideas	70			27
Creative and pro-active - uses initiative	40	20		23
Sees patients more holistically	20	30		19
Ward better organised - less chaotic and calmer	30	20		19
More interested in staff development	50			19
More supportive and caring in relationships	50			19
More contact with - better relations	30	20		19
More knowledgeable of professional nursing issues	40			15
Better leader - more respected, good role model	40			15
Draws on staff's personal strengths	30			12
General morale and confidence higher	30			12

In comparing the two charge nurses, another nurse commented:

"I think X (original charge nurse) was an absolute disaster for lay participation. She didn't have any interest in it whatsoever and it is only since X (new charge nurse) came to this ward ..... you know, every little thing she involves the relatives ..... It is discussed, it's not just done. And the doctors have changed - I think she is changing their attitudes as well. She is so assertive in a nice way and gets things done. She has mellowed their attitudes. X (new charge nurse) has only been there since August and I think that has been the biggest change."
(Nurse: N14(E)p18/19)

Another nurse comments on the new charge nurse's commitment to their professional development and to making new systems work, both issues having been raised by other nurses in the exit interviews. For example:

"X (original charge nurse) was a lovely lady, I liked her, but I was there to do what she wanted me to do and she wasn't doing much for the ward, except coming to work, organising it and going home.
I find X (new charge nurse) makes you think a lot more about your care - the mental, physical and psychological care and gives you time, if that is what you want to go and do it ..... I think it is a really good idea because I think we all have different qualities and if you are allowed to use yours, then you get a lot more fulfilment out of what you are doing. Like if X (staff nurse) was allowed a bit more time to counsel, he might enjoy coming to work more than he does and if I wasn't allowed to counsel, I'd be happy!! I don't like doing it. You know, if I didn't have to go into that patient and do that; that's one of my weaknesses, you see. And sister realises ..... sister is very much into weaknesses and strengths, says 'I'll try and help you get better'. She allows you to do things that you like doing and recognises things that help your learning, experiencing things - it's very useful."
(Nurse: N15(E)p15)

Interestingly the nurses did not find the change to a new leadership easy. It required them to develop new skills and learn new roles. It took away the certainty of the routine of their past practice. It was a time of turmoil on the ward, with inevitable staff conflict as participants were challenged to change their relationships with each other to become more reflective and critical of the care being given, within a supportive environment. However, the turmoil was seen to be positive. For example, the medics picked up on the positive change in the ward atmosphere:

"Firstly, I actually see the sister, whereas I very seldom saw the old one. I mean, she used to hide in the office and didn't go around, so personal contact is much better. And there is the sort of interest of the new sister, I think, who is far more interested in the psycho-dynamics and patient problems of that sort, and of course, she is personally interested in the AIDS problem which we have, whereas I think X (original charge nurse) was rather hostile to that, for reasons I never fully understood. So, yes, I think there is an entire change of atmosphere, leadership, and I think that is almost apparent when you walk on the ward."
(Medic: M3(E)p6)

As stated earlier the field notes also show other positive changes that occurred. First, there was some evidence of lay participation in care starting to be put into practice and staff were gaining confidence in their ability to offer such an approach to care. Second, the health professionals, having been reluctant initially to own the project ideas,

started to demonstrate more initiative in facilitating change and be more willing to co-operate with the research itself. Third, a more democratic atmosphere was created on the ward, with the participants feeling better able to talk to each other about their thoughts, feelings and ideas. Finally the ward's reputation within the hospital was seen to be improving. These issues are described in more detail in Appendix XXII.

SUMMARY

Whilst it cannot be claimed that lay participation in care was fully implemented, nonetheless some positive changes did occur on the ward. Interestingly, whilst medics suggested unanimously that the introduction of lay participation in care was floundering, the suggestion was not held as strongly by non medics (Exit Interviews: N: 30%; M: 100%; P: 33%; J: 58%). It is possible that non medics were more able to recognise that change would be a slow process and perhaps they valued more the small changes that did, in fact, occur.

Overall some important changes occurred which were revealed by both the structured and unstructured approaches to data collection. Structured instruments used to assess change suggest improvements in the ward learning environment, implementation of the nursing process and in the quality of care being given. Other important changes detected by less structured approaches to measuring change include health professionals changing their attitude towards lay participation in care, an improvement in patient education, multidisciplinary teamwork and ward organisation to facilitate lay participation in care. Moreover, the change in ward leadership was seen to be an improvement. However, these changes were not achieved easily and the following chapter reports on the difficulties encountered when attempting to change practice.

CHAPTER 8

DIFFICULTIES OF CHANGING HEALTH CARE PRACTICE

INTRODUCTION

This chapter describes the difficulties of changing health care practice in the case study area. Data were generated from a number of sources namely, questionnaires, interviews and field notes based on participant observation. It is argued that the issues raised concerning the difficulties of changing practice do not relate entirely to the introduction of lay participation in care. As with all case studies, the findings cannot be generalised, but it is hoped that by giving a rich and vivid account of them in their context the reader will be able to judge their relevance in relation to their own practice.

The chapter begins by discussing the data from the initial interviews which summarise the extent to which health professionals believed the ward was ready for change. It then goes on to examine what the health professionals perceived to be the potential difficulties in changing practice. Following this, data from the field notes and exit interviews are used to describe the barriers to changing practice encountered in reality.

WARD READY FOR CHANGE

Interestingly the majority of health professionals stated during the initial interview that the ward was ready for change (Initial Interviews: N=72%; M=79%; P=77%; J=76%). For instance, some of the nurses and paramedics suggested that the ward needed to change, citing that the ward organisation needed to improve and arguing that practice on the ward tended to be inefficient (Initial Interviews: N=28%; M=21%; P=31%; J=27%). Problems requiring improvement included poor multidisciplinary communication and also poor attitude of some staff towards change. Nurses commented that the ward was in a rut and that there had not been enough change in the past (Initial Interviews: N=39%; M=14%; P=0%; J=20%). Whilst some paramedics agreed that the ward should change its approach to practice (Initial Interviews: N=17%; M=14%; P=31%; J=20%), others felt they did not know the ward well enough to comment on this issue (Initial Interviews: N=6%; M=14%; P=38%; J=18%). Of all the groups it was the nurses who claimed to be the most enthusiastic for change (Initial Interviews: N=50%; M=0%; P=0%; J=20%).

Asking participants whether they felt the ward was ready for change led to several making comments about the ward itself. These data provide rich contextual information about the state of the ward in respect of being prepared for change. Table 28 summarises the comments made by more than 25% of any one group of health professionals in relation to the state of the ward in readiness for change.

Table 28: State of the ward in readiness for change - main themes from initial interviews

State of the Ward in Readiness for Change	M %	P %	N %	J %
Poor communication				
Poor communication - MDT	57	62	33	49
Nurses don't know what is happening	36	8	17	20
House officers can't cope - shell shocked - can't communicate	29			9
Tendency towards habit and routine				
In a rut - insufficient change in past	29	23	56	38
House officers - glorified clerk	29			9
Lack of leadership				
Charge nurse reluctant to change - no leader	36	46	11	29
Ward too busy for change				
Very busy ward	29	38	11	24
Staff shortages	36	4		9
Lack of participation in care on ward				
Insufficient contact with families even at discharge	29	31		18
Don't know ward well enough to comment	21	62		24
Lack of teamwork - medical dominance				
Rely on nurses referring patients		38		11
Individuals enthusiastic for change				
Some staff nurses enthusiastic for change			33	13
Participation in care not a new concept				
Work towards involvement in care already	29	8		11
Happens informally anyway - demanded	29			9

M=Medics (14), P=Paramedics (13), N=Nurses (18), J=Joint (45)

The picture that emerged was of a task oriented ward team which lacked both multidisciplinary cohesion and a leader enthusiastic for change. Furthermore there appeared to be some confusion as to whether or not lay participation in care was already being implemented on the ward. Whilst some medics and paramedics suggested there was a lack of lay participation in care even at the time of patient discharge, other medics argued that it was not a new concept and health professionals were already working towards lay participation in care, in response to lay demand. Thus some members of the team believed they were already practising the proposed change. Nonetheless, whilst it appears that the ward was not ready for change, the multidisciplinary team stated strongly that the ward was ready for change and some of the nursing staff were clearly enthusiastic towards the proposed changes. Moreover, when participants were confronted

with their reluctance to change practice, they remained adamant that the project, with its proposed changes, should not be abandoned.

Whilst participants were committed verbally to change, they were nonetheless aware of several potential difficulties at the beginning of the study. The following section examines the difficulties they anticipated and goes on to explore the difficulties encountered in reality.

ANTICIPATED BARRIERS

At initial interview participants were asked to identify the factors that might negatively influence the introduction of lay participation in care on the ward. Table 29 summarises the main difficulties anticipated by health professionals.

Table 29: The main difficulties anticipated by health professionals when introducing lay participation in care - main themes from initial interviews

Anticipated Barriers	M %	P %	N %	J %
Lack of time - requires more effort				
Take more time - insufficient time	36	38	33	36
Staff transience				
Staff move round so much - may not co-operate	29	38	33	33
Shift patterns - hard to communicate		31		9
Reluctance to change				
People may be set in their ways	7	8	50	24
No enthusiasm for change in practice	29	8	22	20
Adjusting to different roles				
Adjusting to different roles takes time	14	31	17	20
Radical change - not done before			28	11
Lay people may not want participation in care				
Patients traditionally passive - may not want it	29	8	6	13
Lack of contact with relatives				
Hard to contact relatives - visit in evenings	14	31	6	16
Lack of enthusiasm				
Done half heartedly - poor repercussions		8	28	13
Inertia due to apathy and different personalities	29	8	6	13
May not be prepared to put in own time - extra effort	7		28	13

M=Medics (14), P=Paramedics (13), N=Nurses (18), J=Joint (45)

All groups of health professionals identified concern that there was insufficient time on the ward to change practice and that staff transience could lead to professionals not co-operating with the project ideas. Paramedics expressed a further concern that "shift" patterns might make the communication of new ideas difficult. Another anticipated difficulty of changing practice was thought to be health professionals' reluctance to change. In particular nurses thought that individuals might be set in their

ways whilst the medics questioned if there was sufficient enthusiasm amongst staff for change. The need to adjust to different roles was also seen as being problematic. Paramedics saw this adjustment as being time consuming and the nurses saw it as being a radical change in their normal practice. Medics questioned whether lay people, who are traditionally passive (refer to Chapter 2), would want to participate in their care. Meanwhile, paramedics questioned whether there would be sufficient contact with relatives to foster this kind of care in practice. Both nurses and medics feared that lack of enthusiasm, shown by some participants, would be a barrier to change. Nurses wondered whether individuals would be prepared to put in the extra time required and feared the repercussions if people did not make the effort. For example, in response to being asked whether the ward was ready to change one nurse said:

N *"I think it needs to change."*

R *"Needs to change?"*

N *"Ya, desperately. Um ..... ya I think it is ready for change."*

R *"In what way does it need to change?"*

N *"I think a lot of things on this ward have just been done over the years and perhaps not much thought has gone into it and I think we all need to be a bit more enthusiastic about what we want and where we're going rather than just carrying on in the old way."*

R *"Do you think it's ready for change?"*

N *"That's difficult to say because until you've got staff nurses and sisters or whatever who are happy working here and willing to change then no, and at the moment we've got so many swapping and changing and not staying here very long that it makes it difficult, but I think it definitely needs it."*

R *"What difficulties do you think we might encounter making these changes?"*

N *"Um ..... I think it's just we all have to accept that we do have to work harder and be a bit more enthusiastic and get some results and I think we*

have to work closer together as a team which perhaps doesn't go on at the moment, I don't know."

(Nurse: N5(I)p9/10)

It is interesting to compare anticipated difficulties in changing practice with what occurred in reality. The following section explores data from the exit interviews and field notes which examined the process of change in reality.

DIFFICULTIES ENCOUNTERED

It is interesting to note that without exception all the anticipated barriers to change identified in the initial interviews became real issues in practice, as identified by the exit interviews (see Table 28) and field notes (see Table 29). However, it is also important to note that at initial interview these issues were raised by a smaller proportion of people (28-38%) compared with exit interview (30-100%). Clearly participants were not able to perceive the extent to which these issues would become barriers to change. Furthermore the exit interviews and field notes revealed other barriers which had not been considered during the initial interviews.

At exit interview participants were asked to describe the difficulties of changing practice that had occurred on the ward as a result of trying to introduce lay participation in care. The difficulties identified by more than 25% of any one group are summarised in Table 30.

Table 30: Participants' perceptions of barriers to change - main themes from exit interviews

Perceptions of Barriers to Change	N %	M %	P %	J %
Lack of time and energy for changing practice				
Too busy with other tasks - low priority	90	100	67	88
Hard to cope with routine without taking on new ideas	10	60	67	42
Unstable work force				
Transience of staff - lack of continuity	40	80	83	65
Reluctance to change practice				
Resistance to change	60	50	67	58
Takes time to change routines and patterns of work	30	50	33	38
People in a rut - been in post a long time	30	30	67	38
Apathy - too much trouble to change	40	30	33	35
Some staff more flexible to change than others	50	40		35
Lack of management support for change				
Lack of enthusiastic leadership	50	60	33	50
Hierarchy slows process of change - inhibits juniors	30	20	50	31
Apathy - nobody making them do it	30	10	17	19
Lack of leadership, monitoring and checking up	30	20	33	27

Table 30: continued

Perceptions of Barriers to Change	N %	M %	P %	J %
Original charge nurse - poor change agent				
Blocked change (LPC)	80	20		38
Negative attitude destructive	30			12
Didn't like authority to be questioned	30	10		15
Just going to work to do a job	30			12
Couldn't see the good of changing pro-active	30			12
Tendency not to consult staff	30			12
Lack of direction and guidance for junior staff				
Poor management - lack of handover and induction	10	30	33	23
Lack of multidisciplinary teamwork				
Professional skills not valued within the team	10	20	60	35
Whole team not pulling together	50	20	17	31
Difficult to get a consensus	30	20		19
Poor environment for change				
Inefficient systems get in the way of change	20	30		19
Competing needs students v staff	30			12
Task oriented and routine based practice				
Medics don't see patients holistically - task oriented	10	40		19
Lack of motivation to develop professional practice				
Just coming to work to do a job and go home	30	10		15

Data from the field notes validates several of the issues raised by participants during the exit interviews, for example, lack of time, staff transience, reluctance to change, and lack of an enthusiastic leadership. Table 31 summarises the main themes from field notes in relation to the barriers to change. A more detailed version is given in Appendix XXII.

Table 31: Participants' perceptions of barriers to change - main themes from field notes

WARD PRACTICE NOT CONDUCIVE TO CHANGE

- Staff set in task oriented approach not professional model
- Transience - no stable work force to develop change
- Lack of enthusiastic support for change from key leaders
- Lack of teamwork - no participation amongst professionals
- Poor ward organisation and management to facilitate change
- Professional conservatism hampering innovation
- House officers in at the deep end - unable to cope with change
- Lack of support for change from nursing management - sweeping issues under the carpet
- Staff lack management skill to support change of practice
- Lack of talking and supportive culture to support change
- Staff recognise own need for support to be able to contribute more
- Poor ward learning environment
- Atmosphere on ward not conducive to change

Table 31: Continued

SYSTEM UNABLE TO SUPPORT INNOVATION
Lack of time and resources to support change
Change is hard to achieve as a one off in an organisation
NHS staff over stretched and stressed - state of crisis and low morale
NHS under constant threat of change - poor environment
Organisation not committed to professional nursing developments
Higher demands placed on staff due to NHS changes - no energy for innovation

One of the greatest barriers to change concerned the health professionals' attitudes towards lay participation in care when confronted with implementing the concept in reality. These issues have already been addressed in detail in the previous chapter and therefore are not explored further here. Thus what follows is a discussion of the other barriers encountered by participants. It is argued that such barriers are likely to inhibit any innovation.

Barriers related to individuals taking part in the innovation

This section explores the barriers related to individuals taking part in the innovation. To begin with the way in which some individuals were reluctant to change their practice is examined. Second, the lack of enthusiastic leadership is described and finally the lack of multidisciplinary teamwork inhibiting change is explored.

Reluctance to change practice

All groups of health professionals identified reluctance to change practice as a major barrier to change (Exit Interviews: N: 60%; M: 50%; P: 67%; J: 58%). Medics suggested that it took time to change routines and patterns of work, and paramedics felt concerned that some members of staff had been in post too long and were likely to be in a rut and reluctant to change. As one medic pointed out:

> *"People are very happy ..... changing anything involves more work than leaving it the same, so therefore unless you make it worthwhile to change something, people will keep it the same. They will do what they know rather than what they don't know. It's just the way things are."*
> (Medic: M25(E)p13b)

All groups described a general apathy on the ward and nurses suggested that some staff were more open to change than others. It was felt that some nurses saw work as a job to be done whereas other nurses felt more committed to the professional development of nursing and were therefore more enthusiastic about change. As one nurse commented:

"I've never felt like a dedicated nurse ..... There's the type who are innovative and always thinking of new ideas and they're dynamic, where I suppose there's a type like me who just likes to do their work, do what's needed and leave it at that. They're not exactly keen ..... The non dynamic ones I think just want to do their job, enjoy themselves while they're there and do their job and go home and generally don't ..... well me I haven't read up an awful lot at home, I haven't done any work outside."
(Nurse: N9(E)p1/2/3)

This reluctance to change practice was further compounded by professional conservatism. This was not something identified by participants at interview but was very much evident in the field notes. Professional conservatism appeared to centre around a fear of litigation and also a threat to professional practice. Professionals expressed a reluctance to pass over their responsibility to lay people fearing the legal implications of lay people doing harm on the basis of little knowledge. Even after positive clarification there was still fear of litigation as described by the new charge nurse in the field notes:

"During the course of a conversation on the telephone X (original charge nurse) highlighted an interesting situation that arose on the ward. A patient had been admitted paralysed with multiple sclerosis. He had a group of carers at home and they wanted to come into hospital and take over the care. X (original charge nurse) at first saw this as a wonderful opportunity to put lay participation in care into practice and wanted to encourage it. She talked to the carers, who identified they needed a special bed in order for them to continue the care they had been giving at home. X (original charge nurse) approached her immediate manager and explained the situation. She was surprised, worried and later angry at the X's (immediate manager) response. X (immediate manager) warned her to be careful because as charge nurse she was responsible for the care given on the ward and would be accountable if anything went wrong. Initially X (original charge nurse) felt extremely anxious and questioned what she was doing; eventually she reflected on the Code of Professional Conduct and stopped being silly. She saw this as yet another example of conservatism stifling change."
(Field Notes: R(F)p812)

Other concerns focused on the changes being seen as a threat to professional practice. Medics were reluctant to allow the development of non-medical ideas on the

ward. For example, aromatherapy was viewed with scepticism as being unscientific whilst health promotion leaflets had to be vetted for fear of conveying conflicting messages.

Whilst there was a general reluctance to change practice amongst some of the participants, another issue concerned the lack of enthusiastic leadership.

Lack of enthusiastic leadership

Lack of enthusiastic leadership was an issue identified as being a barrier to change in both the exit interviews and the field notes. In the exit interviews all groups identified a lack of enthusiastic leadership as a problem (Exit Interviews: N: 50%; M: 60%; P: 33%; J: 50%) and paramedics felt that the hierarchy was slowing down the process of change and inhibiting junior staff from being more enthusiastic. Some nurses and paramedics commented on a sense of apathy existing because there was no one in a position of power seen to be leading and monitoring the innovation. Furthermore the majority of nurses identified the original charge nurse as being a poor leader of change. They suggested that she blocked lay participation in care from occurring and found her negative attitudes to change somewhat destructive. One medic summed up the situation as follow:

M *"It's such a pity, She's set in her ways. I mean when she was away there was a big surge of enthusiasm and there were teaching things going up and a whole list of talks to be given to the students and just a general bonhomie between the nurses and everyone on the ward, and since she got back, that was it, everyone's enthusiasm went."*

R *"Why do you think it goes when she comes back?"*

M *"She squashes it, she dampens enthusiasm because she then starts on trivial things again, and whatever they try to do, it's like banging their heads against a brick wall, because she wants it done the way she wants it done ..... the point is that no-one can have any ideas of their own. You can't work like that. If everything was treated like that, then you do lose enthusiasm, you just get on with mundane things and don't give a damn, you just think, well I'll just get my job done. It shouldn't be like that ..... and there is this negativism all the time. She's frightened that someone is going to usurp her, she wants power and she's frightened of new ideas ..... I'm sure that's why she is so negative about it. Because otherwise I'd have thought she'd receive it with open arms, anything that's constructive*

is worth it. No-one's criticising her, it's not a personal assault at all, but her attitude is affecting everyone. It could be such a good ward because you do get good material to teach on and interesting patients and nice staff."

(Medic: M18(E)p11/12)

The field notes further supported the need for an enthusiastic leader to stimulate change. A dynamic leader was seen to be key in the management of change both in terms of motivating staff and being able to lead, support and monitor the innovation. However, this was a frustrating role that the original charge nurse did not relish as became apparent in a meeting recorded in the field notes:

"Charge nurse said she was fed up of having to nag everyone. She said '..... Do I have to keep going round and telling people how to behave. I have to keep going round telling people to do the teaching, key nursing and participation in care ..... is this what a sister's role is all about? Why can't everyone just get on and do it, they are qualified nurses, why can't they be grown up?' Staff nurse X started to laugh and said 'You can't put all the blame on us. You need enthusiasm and direction from the top. Come on now, you've not been enthusiastic yourself.' Charge nurse said that was why she was getting out, she was fed up of having to nag - it put her under too much pressure and it made her feel let down."

(Field Notes: R(F)p461/462)

When leaders (senior colleagues) were not seen to be supporting the innovation with enthusiasm, participants became disillusioned. The charge nurse became disillusioned with lack of support for the innovation from nursing management, the staff nurses with lack of support from the charge nurse and the junior medics and paramedics with lack of support for the innovation from the senior medics. Interestingly all groups of health professionals appeared to see the charge nurse as being responsible for initiating and monitoring change on the ward. Whilst the consultant clearly saw himself as head of patient care, he did not see himself as a manager of change in ward practice. This was seen as the role and responsibility of the charge nurse who was expected to monitor the junior medics as well as the nursing staff.

"I think it has to come from the ward sister who is there all the time. I think if you have a ward sister who believes this is a thing to do and can motivate her nurses, I think this will be very important in motivating the housemen (sic) because probably if you look at it , the sister and the nurses have as much, if not more

contact with than the consultants, and certainly the senior registrar. So I think that could be a valuable way of educating the housemen (sic) as well as integrating them into the system"
(Medic: M2(E)p8)

However, the hierarchical power structures meant that if the senior medics did not actively support and monitor the implementation of project ideas, junior medics would neglect their responsibilities in the change process. The expectation, by senior medics, that the charge nurse would manage the junior medics as well as her own nurses was a hidden phenomenon, as she did not necessarily perceive she had a responsibility to do so.

Lack of multidisciplinary teamwork

Another major barrier to change was the lack of multidisciplinary teamwork. There was a sense that, unless individuals could work together more closely, change would not occur. The initial interviews (Table 28) revealed communication to be a problem between members of the multidisciplinary team. It is noteworthy that some medics suggested that nurses communicated poorly within the team because they did not always know what was happening. Meanwhile, other medics described themselves as being poor communicators because they felt they could not cope with what was expected of them in practice. For example one medic said:

"I think one of the greatest disasters on this ward is the lack of information that is given at the nursing report. There is certainly no knowledge disseminated 'cause the number of times that we do a ward round and there is just no information available from whichever nurse is on the ward round. To me the "four days off" is not an excuse, that's what report is for, to bring people up to date and if doing the ward round at 2.30 in the afternoon they don't know what's happened in A1 then there's something dreadfully wrong with the system"
(Medic: M4(I)p17)

Whilst communication within the team was thought to improve during the project, at exit interview (Table 30), as at initial interview (Table 26) the paramedics commented that their professional skills were not always valued in the team and they felt isolated within the team. At initial interview many of the paramedics felt they did not know the ward well enough to comment on its readiness for change, whilst others suggested that there was medical domination within the team and a lack of understanding and team collaboration. Paramedics complained that they often had to rely on nurses referring

patients to them and suggested that their roles were not always fully appreciated by medics. One paramedic commented:

P *"I had very little support or feedback from the ward and I think it re-bounded with me not actually giving the input into the patient either, which is not good for the patient, so I mean I'm criticising myself and the ward for that."*

R *"What went wrong do you think?"*

P *"I don't think there is the interest, or was the interest in what my role was for the patient, or knowledge perhaps ..... There was also, I think, a lack of ideology, or difference in ideologies, for example the consultant and his opinion of perhaps what "X" therapy is for and about and what we see ourselves as being about."*

(Paramedic: P14(I)p10)

And at exit interview another paramedic commented:

"Because I sometimes find ..... like I go on the ward, I check through my list of patients - 'Is there anyone else who needs to be seen?' 'Oh yes' ..... but they should have rung down to me or you know, ... rarely get doctors' referrals, which I should get ..... and I think that makes you think 'Well, how important am I?' ..... But that is all wards - you get that everywhere - it's just a few specific areas where you feel definitely more part of the team."

(Medic: M21(E)p9)

Medical dominance is a key issue in the study. The intention throughout the study was to use democratic processes in decision making. However, in multidisciplinary team meetings, medics (in particular senior members), dominated the discussions. Junior medics, nurses and paramedics appeared reluctant to engage in debate for fear of upsetting their perceived superiors. Even when they did not agree with decisions made they would rather express their feelings to me informally than in formal meetings. For instance, when referring to the consultant, one paramedic said:

"I think people are just slightly intimidated. They don't want to say what they really feel in front of somebody who might be in a position to criticise them, or to

say well why do you say that? I don't think that. You don't want to get into a confrontation situation with your superiors, I suppose."
(Paramedic: P13(E)p8/9)

Similarly junior medics were reluctant to make suggestions, which might not be agreed by their consultant, for fear of getting a bad reference. It was considered prudent to remain silent rather than run the risk of compromising their careers by speaking up at meetings. As one medic said:

"I think it's difficult. I've said it to the registrar and the nurses and whatever, I still wouldn't say it to the consultant about ward rounds being run better, you know consultant ward rounds, you shouldn't have foreign students there, you should give more time with the patients and you should speak to the relatives, but I don't feel it would do my career any good to tell the consultant how he should run his ward round."
(Medic: M17(E)p17)

The inability of professionals to communicate openly and honestly with each other was clearly seen to be a major barrier to change. And yet it seems ironic that the project was concerned with lay participation in care whilst the professionals were unable to engage with each other!

Lack of a talking and supportive culture

All levels of staff complained of feeling unsupported. This issue was recorded frequently in the field notes in that participants often turned to me for support in the absence of anyone else. Communication within the team was poor but even across disciplines there was a lack of concern and support for individuals. The field notes illustrate the lack of support for colleagues. For example, following the death of a patient suffering from AIDS, one staff nurse had found more comfort from the patient's relatives than her own colleagues:

"X had been badly affected by his actual death and said that she had cried for two hours and was incapable of working. She had become very close to his friends and she had shared in their grief. She had felt guilty because they were having to comfort her rather than she comfort them. However, as a nurse she felt totally isolated. The other nurses working with her on night duty (agency and third year student) laughed at her for crying and when she went off the ward she had no one to talk to. She had felt desperate and alone." (Field Notes: R(F)p777)

Lack of colleague support appeared to be associated with a lack of communication skills to deal with such issues but also appeared to be further compounded by a lack of time for discussion of feelings in meetings and a tendency amongst management to sweep problems under the carpet rather than confront them. Staff appeared to be unaware of each other's problems and there were not infrequent incidents of inter-staff conflict. These incidents were described as personality clashes but often involved individuals not coping with aspects of their work and not being given support to work through these problems. Several staff complained of feeling burnt out and exhausted. There was a sense that individuals were finding it hard to cope with aspects of there work and yet there were no mechanisms for dealing with this. Managers had their own problems to deal with and were feeling similarly exhausted and the lack of support for colleagues appeared to be evident throughout the organisation. This left some individuals feeling used, abused and demotivated. Some staff were thought to be going off sick on account of not being able to cope with the stresses of work. The lack of support left some individuals feeling frustrated and angry. Interestingly staff recognised their own need for support and sometimes commented that they had found the interview therapeutic as it gave them an opportunity to air their concerns. Other studies report similar findings in respect of the therapeutic effect of interviews (Finch, 1984; Oakley, 1985; Johnson and Plant, 1995). Some participants complained that, in practice, they never had the opportunity to express their feelings and as a result did not feel supported or valued.

Lack of care and support was felt amongst learners, who also found the ward a poor learning environment. They regularly complained to the school of nursing that they were not adequately monitored on the ward and were largely unsupported by staff. They also complained about the lack of professional development on the ward and suggested that some staff, who appeared to be just coming to work to do a job, were not prepared to get involved with teaching and helping them to develop their professional skills. Thus the learners did not find the ward a supportive environment in which to learn.

Barriers related to the environment

Having examined those barriers to change relating to the individuals in the study this section considers those issues relating to the environment. The barriers to change related to the environment include task oriented practice, lack of time, transient work force, lack of management support and low morale. Each of these issues will be discussed in turn.

Task oriented practice

The fact that staff were set in a task oriented approach rather than a professional development model of care was a key issue recorded in the field notes. Participants found it difficult to adopt the proposed system of care because it focused on "patients as individuals" which was incompatible with the "task oriented practice" that prevailed. In particular, it appeared that junior staff hid behind tasks to cope with their day to day work. It was as if they had not been adequately trained to do what was expected of them and once qualified they found it difficult to cope with their new roles. As senior staff appeared to reinforce the importance of completing tasks, junior staff were not interested in jeopardising their careers by subscribing to anything other than task oriented practice. However, as junior staff became more confident in their roles they became more aware of the individual needs of patients and were then better able to think about different ways of practice. Unfortunately staff did not remain on the ward long enough to develop the skills required for a more "patient centred" approach to care. The following extract taken from the field notes illustrates how staff were driven by the notion of task oriented practice:

> *"Went to the hospital today to interview the house officers. They are due to leave the ward after their 3 month allocation. Once more they have shown a typical pattern of adapting into the ward and adopting the project ideas. Initially for the first month they appear to be 'in at the deep end', floundering about, not really knowing what they are expected to do. In order to please the consultants and further their own academic careers they act as glorified clerks, ensuring results are obtained for the ward round. Because systems do not work, they are constantly having to chase after things to get things done. Obstacles are constantly put in their way. As a result they are forced into a task oriented mode and fail to deal with patients in a holistic way. Approaches to care involving education of the patient and their families seem to be the least of their priorities. The second month they have time to listen more to the project ideas but do not see it as having anything of value to offer them. It is perhaps viewed as just nursing research. The fact that lip service is paid to it once a week by the consultant keeps it on the agenda but something that they can afford to ignore. By the third month they start to realise the value of the ideas. They have now worked in 'Outpatients' and can see how frustrating it can be to deal with an uninformed patient. They have begun to realise how little they do know about their illnesses and treatments. They have developed some of the skills needed to talk to lay people and are becoming more involved themselves with the ward. By then it's too late because they are due to leave again."* (Field Notes: R(F)p675/676)

At exit interview 40% of medics said that they had not been trained to see patients holistically and emphasised the routine nature of their work, as the following quotes illustrate:

> *" ..... I understand more about the patient care, whereas before I was just learning about conditions, but now I'm seeing that there's a lot more to patient care than just ..... well I'm learning about patient care, before I was just a medical student and it doesn't really come into it."*
> (Medic: M6(I)p21)

> *"I think a lot of the aspects of what they (house officers) do are so routine and menial, collating information and not actually dealing with the patients themselves, that maybe the patients, ... certain things to do with the patients that actually involve their understanding and their care ..... may be get ..... not neglected ..... but they can't devote as much time to them as they would like."*
> (Medic: M27(E)p5/6)

Similarly some nurses were driven by task oriented practice, illustrated by the unsuccessful attempt to introduce the "key nurse system". Some senior nurses found it difficult to relinquish tasks to more junior staff, for example, arranging discharges, in order that junior staff could give more holistic care to individual patients. The field notes record how attempts were made to manage, in tandem, these two incompatible systems of giving care. Without a leader committed to the new concept of care, nurses were pulling in opposite directions and little seemed to be achieved. Even when it was decided to inform patients and their family and friends, by means of a letter, about there being an opportunity on the ward for lay participation in care, some staff saw this as a task to be performed. As a result letters were just given out without explanation or left on patients' lockers at risk of being ignored. For example:

> *"Since the letter was given out last weekend, very little has happened. Giving out the letter is not enough, patients need to be approached individually and counselled as to what they might wish to participate in whilst in hospital. The key nurses seem to vary in their ability. Some seem to know their patients well, have started to plan their discharge and have spoken to the families. Others are still working in their task oriented roles."*
> (Field Notes: R(F)p352)

Lack of time, energy and resources

The commitment to task oriented practice meant there was little time to develop other ways of providing care. Lack of time, energy and resources to cope with changing practice was perceived by all groups to be the greatest barrier to innovation. At exit interview participants disclosed that they were too busy working with routine tasks to be able to develop new ideas and as a result the project was, for many, low on their list of priorities (Exit Interviews: N: 90%; M: 100%; P: 67%; J: 88%). As one medic said:

> *" ..... at times there almost seems too much to do and I just get on with sticking the needles in people and making sure they've signed consents when they go to theatre, but I don't see it as kind of holistic ..... maybe I should do but I just don't have the time or the resources available to think more about the patient and his environment."*
> (Medic: M17(I)p21)

Similarly the field notes record a lack of time being a barrier to change. In particular there appeared to be a lack of time for adequate discussion in order to plan change. Meetings were frequently cancelled or hurried to such an extent that it was difficult for participants to engage in any meaningful discussions. Paramedics, at exit interview, recognised the need for longer meetings to facilitate discussions, stating this to be a desired change which did not occur.

Participants also complained that the staffing levels were inadequate on the ward and said that they felt constantly too over-stretched to be able to cope with what was expected of them. Staff who left the ward were not always replaced, either because the hospital was trying to save money or because it was difficult to attract staff to work in London. Participants felt that they were so busy trying to keep their heads above water, there really was not any time available to think about new systems of work, and hence they hid behind task oriented practice. Students on the ward complained that there was no time for teaching or reflection on care and qualified staff complained about the lack of time for their own professional development. It was felt that standards of care were poor due to lack of support services. Frequently there was no clean linen available whilst patients were constantly left waiting for porters and for their drugs to arrive from pharmacy. Participants felt frustrated because they could not deliver the care they knew patients deserved and felt guilty because they could not give more time to improve standards of care. As one paramedic said:

P *"Well I think it is just basically that I have got a busy job downstairs which takes ..... I feel guilty in a way when I am not downstairs because I know they are rushed off their feet and perhaps I can give the basic service to the ward, which is fine, but when it comes to doing more, I sometimes think 'Well, should I not be seeing to patients that have been sat downstairs waiting for an hour?' ..... which is a problem."*

R *"And what would you have liked to have done?"*

P *"What would I like to do? Well, I think well, obviously, counselling patients before they go home on their medicines. I don't do that in some areas. Unless nurses specifically ask me, I don't do it, and I think in some areas that would be important. Just for example, there was a patient who went home yesterday and he had two pages worth of TTAs and I am sure if I had sat down and looked at those drugs and talked about them, you know, read his notes and the condition involved, he perhaps wouldn't have been on 'polypharmacy' as we call it. So looking at specific problems more than I do at the moment."*

(Paramedic: P11(E)p2)

It is interesting to observe in the field notes that the original charge nurse early in the study felt pressurised because of time and staff shortages and was not sure if she would be able to get as involved in the project ideas as much as expected by others. The new charge nurse also felt these pressures and had to resort to giving up a lot of her own personal time in order to make the changes in practice she perceived necessary. The lack of time available for change created by staff shortages and increased work load was further compounded by another barrier to change, namely the transient nature of the work force.

Transience - no stable work force

All groups of health professionals, especially medics and paramedics, perceived staff transience to be a major barrier to change (Exit Interviews: N: 40%; M: 80%; P: 83%; J: 65%). Being a London teaching hospital many professionals were allocated to work on the ward for only short periods of time (often as little as three months) as part of their professional development. This however led to a situation where there was always someone new to a job who needed to be introduced to the new concept of care. This proved to be a major barrier to change as new staff would prefer to work in a way more familiar to them and because they would not be long on the ward they could not see any

personal benefit from investing time and energy into changing practice. As one paramedic said:

> *"I was probably there too short a time to grasp hold of the whole thing really because I was probably more interested in getting to know about the physio side rather than any other side, so to be quite honest I probable didn't take much notice of what the other multidisciplinary team. ..... how they ..... what they were actually doing as part of your research thing, so I didn't probably really notice what was going on."*
> (Paramedic: P20(E)p8)

It is interesting to note that in the course of one year of working on the ward, taking into account the entire multidisciplinary team and the nurse learners who made up a significant part of the workforce, eighty five new staff started on the ward and eighty nine left representing one hundred and seventy four disruptions to the dynamics of the ward. This issue of transience not only made it impossible to establish a cohesive work force committed to change but also interfered with the process of the innovation itself. The transient nature of the work force meant that there was a lack of continuity in any teaching programme established for individual patients. As one medic commented:

> *"The problem is that so often that the patients come back to follow up and they see a houseman (sic) or registrar that they have never met before, or may have just changed, who doesn't really know about the problems and they get dispirited having perhaps been trying."*
> (Medic: M2(E)p12)

Poor management

Whilst transience was identified in the exit interviews and field notes as a major barrier to change, another barrier to change concerned the lack of management support for change. This issue came to light when no action was taken on the agreed plans for change. For instance, the medics agreed that they wanted to initiate the medicine reminder card system to improve patient education about their treatments. Despite it being discussed at weekly meetings when new house officers arrived on the ward, the system floundered largely because they were not managed in their work. Similarly the key nurse system and other changes on the ward floundered largely because the ward was not organised in such a way so that the system was efficient nor was it ever adequately monitored. For instance the charge nurse refused to take the key nurse system into account when organising the "duty rota" and so it failed because key nurses were not

often able to work directly with their allocated patients. Furthermore, the charge nurse did not monitor ward activity to see if the key nurses were relating to their allocated patients and frequently organised the work in such a way that made it impossible for them to do so. Whilst these issues are related to the lack of enthusiastic leadership explored earlier, there are other aspects which relate more generally to the environment.

It became clear early in the study that junior staff (nurses, medics, paramedics) were not closely managed and monitored in their work and that systems were not set up to support and develop them in their new roles. Whilst this issue was not brought out strongly by participants, I believe it was a crucial factor in blocking change. Thus it is argued that unless attention is given to the mechanisms involved in the professional development of staff, it will not be possible to initiate change in practice.

Lack of management and support for change, was most felt by house officers when they changed wards. Despite the fact that they were often working in their first job after qualification, there appeared to be no system of orientation to the ward. They were given a minimal handover of the patients by the previous house officer and generally left on their own to sort out priorities and "get on with things". As one senior medic points out:

> *"But I think the problem is that you have someone often you have never met before coming in as a houseman (sic). They start often without any handover at all. They are given a great sheaf of information that they have got to take over. A lot of them may have had experience before but some of them are very inexperienced and often frightened by their inexperience and it takes a long time to settle down. And they are told so many things, it is very difficult when you are told all these things, to tell which are the most important and because the rest of us are busy and we don't always realise the problems they are having and the things they are doing and the things they are not doing. Three months is such an appalling short time to have them. It's not surprising that things don't even start to get right until just before they leave."*
> (Medic: M2(E)p3/4)

It is not surprising therefore that many house officers appeared to shelter behind routines and tasks, focusing on the need to please senior medics (in order to get a good reference) rather than on the needs of patients. It is not necessarily how they wanted to practise but clearly they felt such an approach was in their best interests. For example:

"Ideally, I would like to have all the results and the notes at the end of the day in case something goes wrong in the night, for example, everybody knows there and then what the results are. But that is physically impossible. You know the sort of 'protect yourself' at the end of the day. So when that sort of pressure is around, it is very difficult to be the good doctor and go and sit and talk to patients and say 'how are you, how are you getting along, what are your feelings about your illness' and really get in there in a big way. And in that sense we are failing but what can you do?"
(Medic: M31(E)p3/4)

"But again it's so career, academically oriented in that everybody's doing everything for references, getting higher rather than actually living in the present, living in the here and now ..... I don't like that aspect of medicine ..... It's very pronounced in teaching hospitals. ..... Given the choice, I don't think I would come back and work in a teaching hospital."
(Medic: M26(E)p8)

Irrespective of whether the system of care was the most suitable for patients, it appears that staff were so bound up with the performance of tasks that there was no time available, nor systems organised to manage the re-orientation of the new professional approach to care. Clearly the use of inexperienced transient staff to provide the main bulk of patient care does not lend itself to developing and changing practice. Senior medics did not see it as their role to manage change on the ward, despite the fact that they appeared to hold the most power. Instead it was left to the charge nurse to monitor and encourage the junior house officers to change their practice. As one senior medic said:

"So I think if you are making the consultant the main stimulus for change, then that may fall down from the lack of contact. There would be something to be said, and I think a perfectly legitimate approach to make it sister's responsibility on the ward because traditionally sister has always had a very close working relationship with the housemen (sic), particularly. I would have thought she might be a more effective chivvier of the housemen (sic) . Nobody would mind that, I don't think."
(Medic: M3(E)p6)

Similarly another senior medic identified the charge nurse as the leader of change with a role to monitor and develop the house officers' professional skills:

"Yes, I think if you have a ward sister who believes this is a thing to do and can motivate her nurses, I think this too will be very important in actually motivating the housemen (sic) because probably the sister and the nurses have as much, if not more contact with the housemen (sic) than the consultants, and certainly the senior registrar. So I think that could be a very valuable way of educating the housemen (sic) as well and integrating them into the system."
(Medic: M2(E)p8)

To me this demonstrated the senior medics failing to recognise their responsibility to develop professionally and manage their own staff. Change is unlikely to occur when it depends on junior medics taking notice of the charge nurse. In the present study the charge nurse did not have any formal power or status that was likely to influence the junior medics. Furthermore their main concern was pleasing senior medics with a view to furthering their own future careers.

As with the junior medics, nurses also felt that they lacked management and direction. As one staff nurse said at her initial interview:

"The staff nurses, 'cause I mean I've talked to all the staff nurses and they are all very fed up and you know a lot of people leave and I as a staff nurse, I've been there for two years now, and I've never been appraised, I've never been ..... said you're doing this right, you could improve here you could improve there, so I don't know where I'm going wrong. So I have no confidence in what I'm doing and people say the same thing."
(Nurse: N1(I)p18)

Interestingly when the new charge nurse started on the ward and care was organised around the key nurse system (that is nurses having responsibility for small groups of patients rather than responsibility for tasks), she found that the staff nurses did not have the management skills to support the system of work. She found that when the senior staff nurses were left in charge of the ward they did not have the skills in communication, supervision, teaching and organisation to act as competent co-ordinators of the key nurse system. They appeared ill at ease when supporting and developing junior staff and many felt stressed at being left in charge of the ward. The new charge nurse found that, at first, the staff nurses masked their inabilities and avoided responsibility. She realised they needed supervised experience of being in charge. The need to become more aware of their own strengths and weaknesses and develop better management skills in order to foster changes in practice became the main focus of the

new charge nurse's work. Her interest in the professional development of her staff was in contrast to that of the original charge nurse. She believed education to be empowering and viewed it as an ongoing process. She had recently invested considerable time and energy in her own education by studying, in her free time, for a degree in Health Psychology, whereas the original charge nurse had a reputation for not even attending compulsory inservice study days. It is argued that without the commitment to the management skill of professional development, change was not really possible.

It seems ironic that in order to offer lay participation in care staff need to develop educative, supportive and supervisory roles with patients. These are the same management skills required to develop staff professionally in order to change practice, but from the field notes they appear to be lacking. It is therefore not surprising that the specific change of lay participation in care did not occur. It also suggests that any change requiring new ways if thinking would have been unlikely to occur.

Low morale

The field notes and interviews reveal that constraints were being placed upon people within the hospital which hampered participants from feeling able to change their style of practice. Constraints included a dissatisfaction with the poor physical work environment, uncertainty created by constant change within the health service, feelings of job insecurity due to financial cutbacks, as well as job dissatisfaction created by imposed redefinition of roles and responsibilities. In spite of her efforts to initiate change through professional development, the new charge nurse found that such constraints posed barriers to change which were beyond her control. This left her feeling angry and frustrated, for example,

> *"X described herself as feeling really fed up and was thinking of leaving. She felt she was working in an impossible situation. She was constantly chasing around and checking up that everything was being done on a day to day level. There was no time for development work. On the ward things were improving but only to what they should have been in the first place and she wasn't sure if the system would allow them to take things much further. She felt she was constantly 'banging my head against a brick wall'. I asked if she had heard anything since she had complained about the next off duty (insufficient staff allocated). She told me she had heard nothing but as per usual had chased the matter up to be told the problems were just old problems and it appeared that nothing would be done. This made her feel very angry and unsupported though she wanted to be constructive."* (Field Notes: R(F)p750)

The picture created was a health service that was over stretched and in a state of crisis. There was a sense in which health professionals were struggling to keep their "heads above water" just to keep the system "ticking over". It is argued that it was possibly inappropriate to try and introduce change within this kind of environment. Equally, however, there was a sense in which the proposed change of lay participation in care might have enabled participants to cope better with their work. For example, some professionals wondered if by learning to pass on professional knowledge and skills to lay people, it would be possible to lessen their work load by encouraging others to accept more responsibility for care. As one medic commented, lay participation in care was needed to cope with the predicted shortfall in nurses and paramedics. He conveyed a feeling of despair that problems in the health service were not being addressed adequately, along with a sense of not being in control of events:

> *"Oh, I think moral is something that is very important. I think it's utterly depressing - the repeated problems the Health Service - lack of knowledge about the future, the uncertainty about the future at all levels, be it the question of hospitals being privatised, increasing shortage of school leavers, the long term prospects. I mean, we talked about this right at the beginning as the crucial need for lay participation because we have seen figures, literally in the last week or two of the potential disastrous fall of nurses and other paramedics as a result of the decrease in suitably qualified school leavers, which will have its effect over the next five years. I see no way in which the Health Service is responding, or the government is responding to that challenge. It hasn't been aired at all. It's so close to being on us that I don't see that we are going to be able to ride the storm unless something is done fairly soon."*
> (Medic: M2(E)p11)

The factors responsible for lowering the morale of participants are now addressed.

One factor lowering the morale of participants was the poor physical work environment. Participants were expected to work in conditions where their basic needs were not being adequately met. For instance, the hospital canteen had been closed as a health hazard and temporary measures were in operation for staff and patients. In particular it was a problem for those staff working asocial hours suffered, as one house officer commented:

"Meals are ridiculous for housemen (sic). We are supposed to be sent up sandwiches because the canteen was shut down but nobody ever sends extra sandwiches to the ward. Small things like this, they count, they add up. Nowhere to sit and eat, in a place like this for example. They suddenly add up and you think 'What am I doing in medicine anyway?"
(Medic: M31(E)p6)

Staff were expected to maintain high standards of patient care under conditions where systems worked inefficiently and resources were inadequate. For example, nurses frequently complained of there being insufficient linen and, as the following quote illustrates, medics complained that their decisions were questioned when they requested work to be done.

"So one gets the feeling that one is slightly hassled, especially in the background of the hospital which is running understaffed and I think personally speaking, junior doctors are getting a raw deal. Amongst other things why should a technician question my authority in all respect and say 'Is the blood an urgent one?', when I know it is? ..... Why should a haematologist query things when you really sincerely feel this is an urgent blood sample to give in. You wouldn't be taking it anyway, I mean, I have better things to do than take blood samples ..... But it happens. I mean we have had instances in which people's haemoglobin has been down to six and haematologists, at night, on the technician's side have said 'Do you really want blood tonight?' What are we coming to? So in that sense we feel unhappy."
(Medic: M31(E)p6)

Low morale also centred around there being an enormous amount of uncertainty within the health service. The study was undertaken soon after the introduction of general management. Having undergone such a major upheaval, staff were also expected to cope with a revolution in nurse education (Project 2000) as well as the possibility of moving towards independent trust status. Having worked within a system that had changed very little in the past, health professionals were suddenly thrust into a world of constant change and adjustment to new ideas. The changes were being imposed by government and thus individuals felt unable to control their own destinies. It led to feelings of general anxiety and uncertainty, as illustrated by the following quotes:

"I think everybody perceives that the Health Service is in a time of considerable change. I think it is being seen as a time of cuts, rather than expansion. This makes people, I think, uneasy."
(Medic: M3(E)p9)

"I think the changes generally are governed by the huge uncertainty about what is happening with the NHS in relation to the White Paper ..... There are pros and cons and like a lot of people, I am filled with uncertainty myself as to exactly where it means we will be going."
(Medic: M23(E)p16)

Culturally, the new management concepts being applied to health care did not lie easily with past understandings of its meaning. The notion of determining everything in terms of economic cost was alien to many. Professionals found it frustrating in that they felt they were unable to "get on" with the job they had been trained to do. Furthermore, anxiety and dissatisfaction were apparent at all levels of the hierarchy and the lack of confident leaders perpetuated uncertainty throughout the hospital. As one medic commented:

"I think it reflects on how people feel in the hospital. The uncertainty in X about our finance. I mean the Acting General Manager has given it up because he is not prepared to see through another £2,000,000 of cuts ..... Now I find that pretty depressing; to just work in an environment where you are scraping all the time in that way and ward closures are always destructive and demoralising for staff ..... It's difficult to get enthused. I mean, we are meant to be sitting here providing a good service; we're meant to be ..... to some extent, even if it's clinical research...trying to learn what the right service is, to try and improve the quality of the service ..... All we are doing is shutting wards to save money all the time. You just feel disillusioned."
(Medic: M23(E)p17)

To add to this, individuals felt their jobs were under threat. Due to financial cut backs, services were being rationalised. Theatre lists, wards and even hospitals were being closed down in the London area. In particular the closure of a local hospital meant that posts were "ring fenced" to allow for relocation of staff. This led to added pressure on existing understaffed wards. Understaffing resulted from the establishment of workers remaining fixed whilst work loads had increased. Furthermore, patients were being discharged earlier than ever before and so those remaining in hospital were more sick and

therefore more demanding of staff time. The closure of the local hospital also meant the coming together of two separate cultures. In one culture, where the hospital was much smaller, individuals were viewed as "big fish in a small pond", but with the merger their own identities were under threat by becoming "small fish in a big pond". Furthermore, where more than one team existed for a speciality across the two hospitals, there was a real concern as to who would be allowed to practise and what facilities they would be given. This anxiety was further heightened by much public speculation and rumour at the time.

Another major factor causing low morale was the way in which health professionals' roles and responsibilities were being redefined. It was at the time of the nurses' "clinical grading" exercise (Buchan, 1989) and a general sense of disgruntlement emanated from this initiative, with many individuals feeling undervalued and abused by the system. The exercise in itself was an enormous task and nursing management was unable to give much attention to other aspects of their work. Each member of the nursing staff had to be appraised and interviewed in relation to their job descriptions. Those who were not satisfied with the outcome went on to appeal and thereby extended the whole process, often to no avail. The Unions were very much in evidence and whilst many individuals were happy with their own positions, there was a general concern for colleagues who did not appear to have been so fairly treated. After many years of service, people were looking, perhaps for the first time, at their job descriptions and having to come to terms with their expected roles and responsibilities. For many this led to job dissatisfaction as they realised they could no longer continue to practise in the manner in which they had become accustomed. Many took this personally as the following quote illustrates:

> *"Everything was taken personally ..... People saw themselves being graded for what they were actually doing and that was erroneous and it took quite a long time for people to recover from that. So I think that had the biggest impact on the hospital throughout the year."*
> (Nurse: N15a (E)p6)

The impact of changing roles and responsibilities was felt throughout the nursing organisation. For instance, prior to the Griffith's reforms, the clinical nurse manager in the present study was responsible for four wards and was able to work more parochially. However, after the Griffith's reforms, she was given additional responsibilities and was expected to have a wider working knowledge of the hospital. She was expected to cover for other clinical nurse managers in their absence and act as the duty administrator during

non social hours. This involved a wide range of tasks such as sorting out the bed state, cancelling admissions, dealing with problems related to the support services and taking "press" calls. Furthermore, she was required to attend more meetings in connection with both the hospital and the school of nursing, which was also undergoing radical change. The clinical nurse manager commented that, whilst the demands of the job had increased, the numbers of clinical nurse managers employed to do the job had decreased. She described that in the past she had been one of nine people working at her level in the hospital and responsible for approximately forty staff. Following the Griffiths reform she was one of six and responsible for approximately ninety seven staff. She said that this had led to delegation of duties which in turn led to everybody's roles and responsibilities being redefined. She felt the problem lay in not having enough time to be able to do all the things that were now expected of her. As a result she felt forced to deal with the "now" issues and found that sometimes it was very much a state of "crisis management". She said that often she felt she was not achieving as much as she would like to, mostly due to lack of time, and this affected her sense of job satisfaction. Because of the demands placed upon the clinical nurse manager she was well aware that she was not always able to give staff the support they would like. However, she pointed out that relative to her, they were well supported by being part of a team, whereas she was often working in complete isolation and felt that people did not recognise the pressures under which she had to work. Reflecting on the stories told in relation to low morale, it seems that everyone was at crisis point and were expected to achieve the impossible whilst their hands were tied behind their backs. At the end of the interview the field notes record:

> *"Nurses recognise they are not achieving what they want to achieve and feel dissatisfied. They blame each other for lack of support but there isn't the time available to give it easily. Lack of time means things get swept under the carpet and ignored - it is not being openly acknowledged and recognised that not all problems can be solved. It is not always possible to achieve the standards one knows should be achieved. People are working under pressure, in isolation, unsupported in thankless jobs."*
> (Field Notes: R(F)p787)

It is worthy of note that at interview participants did not appear to be aware of some of the constraints being placed upon them. Lack of time and resources was articulated by many participants but little or no mention was given to the effect of developments within the National Health Service and the outcome of low morale. However, this aspect was very much evident in practice. It was almost as though

participants were so busy trying to cope with every day life that they had little time to reflect, as the following quote reveals:

> *"So wherever you go you have examples of inefficient systems, some which could be avoided; some may not be - but probably problems in all hospitals. And you might say that lay participation in care is important but if you can't get the rest of the structure in order, how can you devote more time to that when there is so much else which needs attention ..... It's in fact just a thought that occurred to me just now but the problems with the hospital structure, administration, etc., manpower, seem so enormous that one wonders whether, I mean as important as it is it takes secondary importance."*
> (Medic: M27(E)p17)

It seems that in general there was a lack of time and resources to support change. The clinical service appeared to be in a state of crisis with staff unable to cope with what was expected of them. As a result staff were under a lot of stress and morale was low. Considerable change was being imposed from above and staff did not appear to have the extra energy to cope with any other innovations. Participants found it difficult to develop a "bottom up" approach to change as they became frustrated with the effort of trying to fight the system in order to change things. Innovation was often hampered by factors beyond their control such as inefficiency created by an unwieldy bureaucracy and a lack of general support for change within the hospital. Some participants felt that attempting "bottom up" change was perceived as deviant within the hospital and tended to cause isolation of innovators. Because the hospital was coping with the effects of cut backs, it did not appear ready to take on new ideas. As a result it did not actively support professional development.

SUMMARY

This chapter describes some of the difficulties of changing health care practice. Barriers to change encountered in this action research study include those barriers related to the individual participants and also the hospital environment under study. Issues concerned with individual participants include the participants' general reluctance to change practice, a lack of enthusiastic leadership to guide the change and poor multidisciplinary teamwork. Barriers in respect of the environment include the routine and task oriented nature of health care practice; a lack of time, energy and resources; the transient nature of the work force together with a lack of management support for change and a hospital environment which, due to economic crisis, was not actively supporting

professional development. As a result of these factors participants tended to cling to the known rather than moving into the unknown. For example:

> *"I suppose when you have got your routine as it is, it's always difficult to change any system that already exists anyway and if you're short staffed or you're just incredibly busy and you're rushing around, it's easier to be able to do it in the same old way, because if you introduce anything, it always takes longer at first until you get into the habit, and I suppose if you are going to choose between a system that takes longer and a system that's quicker, you always go for the quicker one - even if it is the old way. If you had staff that were there and they never rotated and they were confident, then you might find it easier but you have to just keep starting again with whatever staff you have, constantly starting again, so I assume that must have been one of the stumbling blocks, anyway."*
> (Paramedic: P21(E)p6)

It is argued that many of the barriers to change encountered would have probably hampered any planned innovation. Thus the findings, related to the difficulties of changing practice, may be of relevance to others wishing to introduce change in a similar health care setting, whether or not the innovation involves lay participation in care.

However in the present study the health professionals' perceptions of lay participation in care were viewed as an further barrier to change (see Chapter 6). Whilst participants claimed to hold positive views in theory towards lay participation in care, when probed more deeply, they expressed some serious reservations about the concept. For instance, health professionals doubted that lay people would wish to be more involved in care and suggested there was a lack of suitable patients. Furthermore, they questioned whether lay care might be as good as professional care. Interestingly, when confronted with applying the concept in practice, health professionals demonstrated a limited understanding of lay participation in care and appeared to lack the necessary skills to facilitate the concept in practice. Thus, the health professionals' perceptions of lay participation in care was also a significant barrier to change.

Although there were many difficulties encountered when attempting to change health care practice, nonetheless, some positive changes did occur. For instance, improvements were made in the health professionals' attitudes towards lay participation in care, patient education, multidisciplinary teamwork and ward organisation (see Chapter 7). However, such improvements as were made were considered insufficient by participants and there was a general perception of little change having occurred.

In the next chapter the findings are discussed in the context of the relevant literature. The need to enhance greater awareness amongst health professionals of the underlying values and principles of lay participation in care is explored. The need to create cultures in hospitals which are more conducive to and supportive of change is also addressed.

CHAPTER 9

BEYOND THE RHETORIC

INTRODUCTION

As discussed in Chapters 6, 7 and 8 several important findings have emerged from the study. These centre around the problems and barriers encountered when attempting to change an aspect of health care practice. Failure to achieve significant change appears to have been influenced by the health professionals' limited understanding of lay participation in care and also by a variety of organisational constraints. This chapter explores the need to move beyond the rhetoric and to enhance greater awareness amongst health professionals of the underlying values and principles of lay participation in care. It also addresses the need to create cultures in hospitals which are more conducive to and supportive of change.

LAY PARTICIPATION IN CARE: THE HEALTH PROFESSIONALS' PERSPECTIVE

Findings from the study suggest that health professionals may be paying mere lip service to the notion of lay participation in care. Reasons for this lack of commitment to lay participation in care in practice may be due to professional ignorance, fear of a government conspiracy to continue to reduce professional services and inadequate preparation for such practice.

Paying lip service to lay participation in care

Findings suggest that health professionals are theoretically positive towards the concept of lay participation in care but in the reality of practice exhibit serious doubts and concerns as to its suitability for health care practice. Some health professionals question the social acceptance of lay participation in care and doubt that lay care is as good as professional care. Furthermore some health professionals do not understand what is meant by lay participation in care and do not appear to have the necessary skills to offer such an approach to care in practice.

These findings question the validity of previous research which has examined health professionals' attitudes towards lay participation in care (Pankratz and Pankratz, 1974; Citron, 1978; Linn and Lewis, 1979; Brooking, 1986). Such studies have used structured instruments and have reported health professionals to be positive about the concept of lay participation in care. By triangulating the data using a variety of methods

(questionnaire, interview and participant observation), the present study has demonstrated that what health professionals think in theory about lay participation in care may be very different to what they feel and do in practice. Thus the need to explore lay participation in care in more depth and in the reality of practice has been justified. This finding not only has important implications for practice but also raises methodological issues for future research which explores people's perceptions of other complex phenomena.

If lay participation in care is to become more than professional rhetoric, there is clearly a need to deal with health professionals' concerns about its use in practice and to better prepare and facilitate health professionals for its implementation. The involvement of patients and their family and friends represents a radical change in health care and there is a need to address other wider organisational issues as the following quote illustrates:

> *"Right, well, as far as I see, I never actually saw lay participation taking place on the ward - I don't think we got that far ..... With the rest of the ward, I didn't really see it, I think there were other things that got in the way because the whole structure, the whole system had to change ..... when you think about it, you'd think it to be quite simple, it just never really seemed to take off."*
> (Paramedic: P21(E)p3)

Currently lay participation in care is being advocated by government in the guise of consumerism (Department of Health, 1989) and by some of the professional bodies in the guise of health promotion (Royal College of Nursing, 1985; United Kingdom Central Council for Nursing, 1986). It is heralded by nurse academics as the new approach to nursing (Beardshaw and Robinson, 1990a) and is seen to be an important aspect of future health care practice (Department of Health, 1993a; Department of Health, 1993b). However, findings from the study suggest that lay participation in care is not part of every health professionals' practice and that health professionals might find it difficult to incorporate it into their everyday work.

By articulating positive views, whilst at the same time holding some serious reservations, health professionals can be seen to be paying mere lip service to the concept. This would appear to be due, in part, to professional ignorance.

Professional ignorance

It is suggested that some health professionals find it difficult to articulate what is meant by lay participation in care and have a superficial understanding of the concept. In

the literature lay participation in care shifts the boundaries in health promotion from the expert directed, paternalistic, prescriptive to a more client-centred, participatory and participative approach (Beattie, 1991). Thus a change in relationship is identified between professional and lay person based on such concepts as "self help", "demedicalisation", "deprofessionalisation", "democratisation" (McEwen et al., 1983), together with such concepts as "emancipation" and "empowerment" (Beresford and Croft, 1993). However, participants in the present study tended not to draw out these underlying ideologies thus indicating a degree of professional ignorance. These findings are supported by two national studies which indicate that nurses do not espouse the values of partnership and participation in their work (Gott and O'Brien, 1990; Latter, 1993). The lack of philosophical understanding is particularly alarming given the current emphasis on health professionals taking an active role in health promotion based on partnership between the public, professionals and policy makers (Department of Nursing Division, 1989; RCN, 1989; Department of Health, 1990; Jacobson et al., 1991; Department of Health, 1992.

Maxwell and Weaver (1984) identify three levels of involvement: patient; family and friends and public participation (see Chapter 2). It is interesting to note that in the study health professionals assumed patients to be involved in care and focused more on family and friends' involvement in functional tasks rather than involvement at the level of public participation. Given that patients have repeatedly complained about lack of communication in hospital (Ley, 1988; Health Service Commissioner for England, 1994), health professionals are perhaps mistaken in their assumption that patients are already involved in their care. By focusing on the involvement of family and friends in functional tasks rather than public participation, health professionals demonstrate a limited view of lay participation in care which suggests they take a more individualistic approach to health promotion than a social change approach. Again this finding is supported in the literature on health professionals understanding of health promotion in acute settings (Gott and O'Brien, 1990; Latter, 1993). This issue is of particular concern given the significant scientific evidence about the relationship between causes of ill health and declining socio-economic status as opposed to the need to change individual behaviour (Hunt, 1992).

Public participation is involvement at the level of community or society and includes: consumer protection; public consultation; openness in managerial decision-making; full management participation by public representatives; and heightened individual responsibility and power (Maxwell and Weaver, 1984). Triangulation of data suggests that not only are some health professionals unable to articulate their involvement

in public participation but, with the exception of consumer protection (which represents the lowest level of public participation), health professionals actively inhibit this kind of involvement. For instance, the health professionals' interest in consumer protection is illustrated in the way in which they were anxious to consult their legal advisors in case harm was caused to a patient through lay involvement in care. However, the cynic might argue this action was motivated more by professional protection rather than a fundamental concern for the consumer.

The way in which some health professionals actively block other kinds of public participation can be demonstrated by lay participants not being actively encouraged to give their opinion of the service and also not being invited to participate in managerial decision-making. Furthermore there was no systematic lay evaluation of service provision and despite the fact that the ward tended to deal with specific client groups, no mechanisms existed for them to share in the processes of health policy making and service provision. In general a paternalistic approach was taken as illustrated by the vetting of the health education materials and the concern about messages which conflicted with medical opinion. These findings suggest that health professionals might not have a full understanding of the different levels of lay participation in care and find some aspects to be a threat to their professional practice. Thus they appear reluctant to relinquish their control over practice, suggesting a preference for the continuation of medical dominance (Engels, 1977) and the existence of an occupational elite (Harrison et al., 1990). Taylor (1979) discusses how hospitals remove control from patients rather than empower them and suggests that health professionals prefer patients to be co-operative and dependent. Recent research examining the interactions between nurses and patients suggests that the power dimension inherent in the relationship constitutes a barrier to open and meaningful communication between nurses and patients (Hewison, 1995). Given that health professionals are actively being encouraged to relinquish some of their control by professional bodies, both in respect of the emphasis on partnership in health promotion (United Kingdom Central Council for Nursing, 1986) and consumerism (Department of Health, 1992), there is an urgent need to address the socialisation of health professionals.

Findings from the study also suggest that some health professionals doubt if patients, their families and friends can be suitably involved in care. Because lay participation in care was never properly implemented on the ward under study, it is not possible to comment on whether there would have been a lack of suitable patients, family and friends in reality. However, given that the health professionals in the study believed participation in care required lay people to be physically "doing something", a limited

understanding of lay participation in care is once again revealed. Such limited understanding is based on professional ignorance and probably accounts for the health professionals' perception that there was a lack of suitable lay people for involvement in care. Lay participation in care does not only concern involving patients, their family and friends in physical tasks. It also concerns professionals enabling lay people to take control of the decision making processes in respect of their care. It involves expert professionals passing on their knowledge and skills to lay people with a view to promoting their sense of well being and health. Paradoxically a decision taken by the lay person not to be involved in care is in itself an example of lay participation. Thus lay participation describes an approach to care which engages all those concerned with the patient's care and therefore when health professionals suggest there may be a lack of suitable people to participate in care, they demonstrate a lack of knowledge and understanding of the concept.

Professional ignorance is also revealed in the way in which the health professionals claimed patients to be already involved in care. This would suggest that practice on the study ward was in some way different to normal practice. This however is unlikely. Research has repeatedly shown that patients are not involved in care and, in particular, patients are excluded from the decision making processes in that they are not being given sufficient information (Davis and Fallowfield, 1991). An alternative explanation might be that the health professionals failed to have insight into how some patients might become more involved in their care. Empirical evidence from the study suggests that there was a need for lay participation in care. Out of six hundred and ninety admissions in a period of one year 67% of patients were discharged home and only 38% were expected to return to the hospital for an outpatients' appointment. Therefore there must have been many people who needed education about their illness and information on how to cope at home following their discharge. Given also that the vast majority of illness is chronic, and therefore people are unlikely to recover completely (O'Neill, 1983), many patients in the study were likely to have needed professional time and support in adjusting to their new lifestyles. Furthermore, in view of the fact that the majority of care in the community is given by informal carers, usually family members and women in particular (Parker, 1985), there may well have been a role for health professionals to prepare not only the patient for discharge but also the patients' family and friends. However, the field notes did not reveal much evidence of this in practice.

Whilst the health professionals may have had a limited understanding of lay participation in care, there may also have been some marginal differences between health professional groups. This may warrant further exploration. Whilst such tentative

differences were not apparent in the findings from the Patient and Family Participation in Nursing Care Scale (Brooking, 1986), at interview there was some evidence to suggest that some nurses and paramedics were more familiar with and had a broader understanding of the concept compared with medics. For instance, in the present study, nurses seemed to have a better understanding of lay participation in care in that they perceived it as an approach to care rather than a set of physical tasks. Meanwhile, paramedics claimed that lay participation in care had been very much part of their training and recognised it as part of their job. However, in contrast, medics had a greater tendency to view lay participation in care more in terms of a cost effective measure to help with shortages of nursing staff and tended to emphasise a greater degree of medical control in decision making rather than recognising it as patient empowerment. Thus it would appear that epistemological confusion abounds and clearly there is a need for health professionals to take stock and reflect jointly on their roles and responsibilities (Gallagher and Burden, 1993) when considering lay participation in care.

The results of the study clearly have implications for pre-registration and post-registration education. Common core curricula for nurses, medics and paramedics with joint interprofessional teaching would perhaps promote a better understanding. It is disappointing that the issue was not highlighted in recent recommendations on undergraduate medical training (General Medical Council, 1993). However, it is argued that merely addressing professional ignorance through education is unlikely to be entirely successful and may lead to further meaningless professional rhetoric. Alternatively, a resocialisation of health professionals is needed to encourage them to question practice and work interprofessionally so that mutual understandings and common philosophies of care can be established. There is also an urgent need for higher levels of interprofessional collaboration at practice level to establish common approaches to patient care in both hospital and community settings. Such shared approaches might best be developed through quality assurance methods (Bloch, 1977) although the process and outcome of change might be more usefully disseminated through action research.

Unless health professionals develop a broader understanding of lay participation in care they will not be able to translate the ideas into practice effectively. For health professionals to claim to be positive about lay participation in care in theory is not enough, since paying mere lip service to the concept will fail to empower lay people to become more involved in their care.

From the above it can be seen that the health professionals in the study have a limited understanding of lay participation in care and seem to lack commitment to

applying the principles in practice. In deconstructing the health professionals' perceptions of lay participation in care, professional ignorance is identified, which might explain why some health professionals appear to be paying mere lip service to the concept.

The conspiracy theory

Another possible explanation for the health professionals' lack of commitment to the concept is their fear of a government conspiracy to continue to reduce professional services. Whilst health professionals espoused positive views they none the less held some serious reservations about implementing lay participation in care in practice. This lack of commitment could be linked to two politically conflicting historical legacies underpinning the development of lay participation in care and also to a desire by professionals to maintain control and preserve their professional status. This explanation can be linked to the theory that health professionals fear a government conspiracy.

The development of the two historical legacies which underpin lay participation in care has been explored in Chapter 2. They embrace the humanistic approach emphasising self-determination and the bureaucratic approach emphasising controlling costs, outcome and efficiency (Van den Heuval, 1980). Whilst both legacies have produced the present concept of lay participation in care, they represent differing philosophical and political perspectives. This thesis suggests that some health professionals are suspicious about the motives underlying the notion of lay participation in care in practice and as a result lack commitment to the concept. For instance, when health professionals were asked about lay participation in care from the perspective of either the patient or family and friend, the perceived disadvantages were largely motivated from a humanistic view. They expressed concern for the invasion of privacy and also a fear that lay people might interpret such actions as being driven by a bureaucratic need for economic stringency; in other words health professionals off-loading their responsibilities onto lay people. They felt lay people would resent being asked to be involved in care and would perceive it as an added burden. Furthermore health professionals doubted whether lay care could be as "good" as professional care and because of their humanistic concern for the quality of care, did not wish to involve lay people in it. On the other hand, disadvantages tended to be recognised by the professionals from the bureaucratic perspective. For instance, some health professionals were reluctant to communicate more with patients and their family and friends because it would be too time consuming. They also feared that an increased presence of lay people on the ward might be too disruptive.

Clearly health professionals were drawing on ideas from both historical legacies to understand lay participation in care, which gave rise to some doubts and concerns about its real value. Most health professionals are likely to value humanism, but in a rapidly changing health service, which emphasises cost effectiveness, the pressure to work in a less humanistic manner is ever increasing.

Interestingly there is some evidence in the exit interviews and field notes to suggest that lay people do not actually wish to participate in care and may perceive it to be an added burden. It is very difficult to make further comment on this without further research. But it could be that lay people did not feel positive about lay participation in care because they did not fully appreciate what it meant or because they were not being offered it by the health professionals in an appropriate manner. The health professionals in the study did not seem to appreciate that lay people who refused to participate in care were paradoxically being involved in care through the process of arriving at that decision. Given that the health professionals had difficulty in understanding what is meant by lay participation in care, it is likely that the lay public were also unaware of what was being offered. Thus these findings should be viewed with extreme caution.

It has been argued that lay people are positive about participating in their care (Brooking, 1986). However, it is interesting to note that in Brooking's study the nurses were the most positive about lay participation in care, followed by the relatives and finally by the patients. As the present study indicates the findings need to be interpreted with caution given that what people respond to in theory may well be different to what they do in practice. Furthermore, other research has shown that lay people may be reluctant collaborators with participation in care, in that they feel coerced into agreeing with the professionals' wishes that they should be more involved (Waterworth and Luker, 1990). However, this finding should again be viewed with caution on account of the small sample size (twelve interviews). Furthermore since coercion is not compatible with lay participation in care, it would appear that the respondents in this study were not being offered "true participation". Thus the respondents clearly did not have a proper understanding of the concept and so were probably not in a position to make comment on such an approach to care. Interestingly, another (albeit a small-scale) study which focuses on the relatives' experience of hospitalisation and discharge of stroke patients, suggests that the involvement in rehabilitation of supporters of stroke patients seems slight and where it does occur it is motivated by the desire to fulfil the patient's needs which are not being met by the health care system (Flatley, 1993). May (1995) suggests that patients may not see themselves as active, collaborative, partners in care, or as experts in their own health. Furthermore, he argues that patients may perceive the realm

of psycho-social care as an intrusion into their privacy. In a series of papers by Armstrong (1983; 1984; 1987), individualised nursing care is seen to have emerged as a result of historical changes which have substantially altered the way that being a patient is defined. However, May (1995) questions whether patients might choose to resist new approaches to nursing care, based on individualisation and thus highlights a tension between "new nursing" and "new consumerism".

Thus when considering the lay perspective on participation in care the evidence is conflicting and inconclusive. Clearly there is a need for further research to explore the relationship between the lay person's understanding of the concept and their acceptance of it in reality. It could be argued that if at present lay people do not really know what is meant by participation in care, there is a need not only for professional resocialisation to be able to facilitate the concept but also a re-education of the public to reorientate their expectations of health care.

The community nurses similarly expressed views which supported both the humanistic and bureaucratic perspectives of lay participation in care. For instance, they felt that in hospital, patients' rights were ignored and they welcomed the idea of empowerment being brought into the hospital setting. These expressed views appear to be in line with humanistic thinking. However, the community nurses also expressed the view that lay participation in care was necessary due to economic stringency. Thus they tended to focus on lay involvement in the physical aspects of care only. They commented that patients were often discharged home with unrealistic expectations of what could be provided in the community. They doubted, in the same way as the hospital health professionals, whether the lay public would be willing and/or able to participate in care. However, they suggested that in the community, lay people do not have the choice. Community nurses argued that it would make their lives easier if lay people were better prepared for the realities of their discharge home and it would seem therefore that lay participation in care in the community is being led by bureaucratic necessity rather than being driven by humanistic worth. The question raised is whether policy makers are disguising lay participation in care as humanistic health promotion when in truth it is being introduced on account of its cost effectiveness and economic stringency.

This argument may indeed partly explain why the health professionals in the present study failed to act upon the policy on lay participation in care which was arrived at collaboratively through discussion. It could be that whilst the health professionals were unable to articulate their concerns, they nonetheless sensed an underlying conflict between the two historical legacies. If health professionals have concerns about the

underlying philosophies and politics of lay participation in care, there is an urgent need for them to vocalise them publicly. If recent writers on health policy are correct in thinking that government is using new managerial approaches (efficiency savings, cost improvement programmes, performance indicators, general management, internal markets which emphasise consumerism) to delay or avoid a crisis in the welfare state (Harrison et al., 1990), health professionals may regret not articulating their views on lay participation in care. Others are similarly concerned about political power distorting the philosophy of health promotion (Cribb, 1993). Cribb uses a Foucauldian analysis of power and social control to explore health promotion as a technology of control. He argues that interventions initiated by government are legitimised by talk of "participation" or "empowerment" and yet mask a new form of social control. For lay participation in care to move beyond the rhetoric, there is clearly a need to unravel the philosophical and political underpinnings behind the policies that advocate lay participation in care and explore the acceptance of these ideas with those people who are largely responsible for policy implementation, namely the health professionals themselves.

Another reason why health professionals need to be consulted urgently about their views on lay participation in care is the fact that some health professionals appear to be threatened by the concept. In the present study some health professionals were reluctant to hand over power to lay people on account of greater public scrutiny which might reveal individual fallibility and failings. This finding is of serious concern given that lay participation in care requires openness both from the humanistic perspective of health promotion and from the bureaucratic perspective of public accountability. If health professionals continue to feel threatened about handing over control to lay people, there is unlikely to be much progress beyond the rhetoric of lay participation in care.

Thus it is argued that health professionals fear a conspiracy by the government to involve lay people in their care for reasons of cost effectiveness rather than improved patient care. They also fear a conspiracy to undermine their own professional power base. Apart from professional ignorance, there may indeed be other factors which account for health professionals paying lip service to the concept.

Linking lay participation in care to interprofessional participation

Another possible explanation for lay participation in care not moving beyond professional rhetoric is the fact that some health professionals appear unable to participate with each other. Whilst participants claimed there had been positive changes in multidisciplinary teamwork as a result of the action research study, nonetheless poor interprofessional participation was seen to be one of the greatest barriers to change. In

particular poor communication, lack of role appreciation and medical dominance within the multidisciplinary team were all identified as important factors contributing to a lack of interprofessional collaboration. This lack of multidisciplinary teamwork is seen to be problematic when introducing lay participation in care. Participants questioned how they might facilitate lay participation in care when there was little participation in care amongst professionals. It is argued that this lack of cohesion in the multidisciplinary team would have been a problem in co-ordinating any form of change and as such should be an issue for all policy makers wanting to introduce change. However, it is questionable whether professionals are capable of offering a change in practice (which involves empowering lay people) when some members of their own multidisciplinary team are not sufficiently empowered to collaborate with each other. Viewed in this way participation in care is not for lay people only but also requires professionals to participate more with each other.

Poor interprofessional relations have been discussed in the literature over the past thirty years (Stein, 1967; Freidson, 1970a; Hoekelman, 1975; Evers, 1981; Kalisch and Kalisch, 1986; Mackay, 1990; Stein et al., 1990; Porter, 1991; Carter, 1994). Whilst most of the literature refers to doctor-nurse relations, it is clear from articles related more specifically to paramedics that they share some similar difficulties (Ovretveit, 1985).

It is suggested that the key problem in poor interprofessional relations lies in the lack of understanding of each other's role in the provision of health care (Hoekelman, 1975). It is believed that difficulties arise due to the different assumptions held by each profession and the different vocabularies used to describe similar problems (Gilchrist, 1978). However, much of the literature discusses interprofessional difficulties in relation to power differences.

Freidson (1970a) has proposed that, due to its autonomy of expertise, the medical profession dominates other occupations within the health division of labour. However, Keddy et al. (1986) in their study of the evolution of the doctor-nurse relationship suggest that a sex role stereotype of the nurse has emerged. Gamarnikow (1978) embeds this in a history of nineteenth century nurse-patient relationships which bares striking similarities to the husband-wife-child relationships within the Victorian patriarchal family. It is argued that this initial construction of the doctor-nurse relationship has had lasting consequences of unproblematic subordination (Dingwall and McIntosh, 1978). Kalisch et al. (1986) believe that the stereotypical image of the nurse as the doctor's handmaiden not only influences the consumer's view of nursing but also the image nurses hold of

themselves. This image is further explored by Salvage (1985) who identifies three stereotypes of the nurse: the innocent angel, the sex symbol and the frustrated battle axe.

However, Stein (1967) notes that some nurses do learn to show initiative and offer significant advice to medical colleagues, whilst appearing to defer passively to the doctor's authority. But more recently Stein et al. (1990) suggests that nurses are not passively accepting external control over their profession and have begun to challenge the medical hierarchy. Other research has shown that in a variety of settings including mental health, accident and emergency and intensive care, nurses hold more influence than previously indicated in the literature (Towell, 1975; Hughes, 1988; Porter, 1991). However, others have found rigid distinctions of status and power between physicians and nurses which have tended to limit communication and collaboration (Devine, 1978; Evers, 1981).

Research in this area appears to be conflicting but it is possible that a gradient of behaviour exists (Hughes, 1988). This is supported by Porter (1991) who in a review of the literature suggests there are four major ideal types of interaction between nurses and doctors in the decision making processes. They are unproblematic subordination, informal covert decision making, informal overt decision making and formal overt decision making. Porter tested each type of behaviour against empirical data and found that whilst both the unproblematic subordination and informal covert decision making type of interaction appeared superficially to be used often, with the exception of nurse-consultant interactions, nurses were less dependent on these subordinate modes of interaction than commonly believed.

Similarly Carter (1994) has examined how doctors and nurses maintain, or challenge, patriarchal relationships in a clinical context. She suggests that whilst the wider social climate upholds the subordination of women in a caring environment, the implementation of alternative therapies, emphasis on patient education, rehabilitation and individualised care have created a nursing domain which alters the power dynamics of interprofessional relations. She highlights the way in which research-based practice and the introduction of Primary Nursing have demanded a different and collective approach to patient care.

However, in the context of physiotherapy Ovretveit (1985) questions whether medical dominance has declined as a result of the increasing autonomy of other developing health professions. He argues that whilst some aspects of professional

autonomy in physiotherapy have developed during recent years, there is no evidence of a significant decline in medical dominance in health services.

It is argued that changes in the status of women, changes in health care delivery and the nurses' bid for professional status could have a significant impact on multidisciplinary relations. However, for non medics to be viewed as legitimate consultants and colleagues in the health care team, multi-level interventions which address the social, institutional, interpersonal and personal factors involved are required (Ryan and McKenna, 1994).

In examining common areas of conflict between doctors and nurses Mackay (1990) identified the following: summoning the doctor, requested tasks not carried out, attitudes towards patients and their relatives, and differences in opinion regarding specific treatments. Similar issues were raised in the context of the present study. Until health professionals share common understandings of each other's roles and work towards common philosophies, showing mutual respect and equal regard, change will remain a threat and will be difficult to achieve. It is clear from the research investigating medical students' attitudes towards nursing work (Ryan, et al., 1994) and the research which suggests student nurses are groomed for subordination (Buckenham and McGrath, 1983) that there is a need to influence more positive attitudes towards nurses in medical training, possibly through interdisciplinary teaching (Leninger, 1971; Scott-Wright, 1976; Gomes, 1985). Nurses also need to learn to grasp any opportunity given to enhance their power and practice (Keen and Malby, 1992) and make more explicit the roles they have to play in the multidisciplinary team (Titchen and Binnie, 1993). There is evidence to suggest that nurses, who in response to changes in the health service are introducing new methods of work (such as primary nursing), are reporting more collaborative relationships within the health care team (McMahon, 1990).

It is argued that participation amongst professionals is a prerequisite for lay participation in care. If health professionals exert power over their professional colleagues then it is possible that they may also exert power over lay people. Until interprofessional and intraprofessional relationships are addressed, lay participation in care is unlikely to move beyond professional rhetoric. In other words participation in care is not for lay people only. It also requires a radical resocialisation of professional practice.

Where there's no skill there's no way

A final factor which accounts for health professionals paying lip service to lay participation in care is their lack of educative and supportive skills in offering to patients and their families such an approach to care. Contrary to the saying "where there's a will there's a way", this thesis argues that even if health professionals are willing to offer lay participation in care, at present some apparently lack the skills to do so.

First, health professionals in the study appeared to lack the necessary communication skills to offer holistic care. Health professionals did not always feel comfortable listening to patients, helping them come to terms with their situations and deciding what was best for them. Poor communication between health professionals and lay people has been the greatest source of complaint to the National Health Service Ombudsman for many years (Dickson et al., 1989). Studies of communication in hospital settings have shown the average rate of patient dissatisfaction with medical communication is 38% (Ley, 1988) as well as the failure of doctors to discuss patients' feelings, life-style and daily situations (Waitzkin, 1984). Other studies examining the communication skills of nurses in hospital settings have shown the quality and quantity of nurses' interaction to be lacking (Macleod Clark, 1985; Maguire, 1985). If health professionals are unable to communicate with lay people and explore issues from a personal perspective, it is not surprising that they appear to lack the skills to offer lay participation in care.

Second, the health professionals lacked the teaching skills required to fulfil their educative roles. Not only did they lack teaching skills in respect of lay people, but they also lacked confidence with respect to teaching junior colleagues. The health professionals also appeared to find it difficult to assess, plan, implement and evaluate care for individuals. Whilst the benefits from patient teaching have been substantiated (Wilson-Barnett and Oborne, 1983) and the nurse identified as having a key role to play (Smith, 1979), studies indicate that nurses are not adequately fulfilling this role (Close, 1988).

Third, for many health professionals lay participation in care represents a new way of thinking and they may find it difficult to break away from their tendency to be prescriptive in advice and authoritarian in manner. This mental set clearly affects the manner with which they present themselves to lay people both in their educative and supportive roles. Given that lay participation in care is based on equality and democracy, such an approach is not conducive to lay participation in care and this was another factor that resulted in a lack of skills to facilitate such an approach to care. It is interesting to

note that some professionals had similar difficulties when relating to each other. This again raises the question as to whether or not professionals can offer such an approach to care when they have not yet learnt to participate with each other.

These findings raise some important issues. If health care professionals do not have adequate communication skills to elicit and understand problems from a patient or client perspective, it is unlikely that lay participation in care can ever be realised in practice. Furthermore if lay participation in care is concerned with developing an "educative and supportive role" rather than a "doing role", the apparent lack of teaching skills will seriously jeopardise the implementation of the concept in practice. Lack of teaching skills amongst health professionals has also been identified in other research studies. It has been argued that in nursing poor teaching skills have resulted not only from a lack of communication skills but also a poor knowledge base (Faulkner and Ward, 1983; Gleitt and Graham, 1985; Macleod Clark et al., 1985). Teaching skills are required not only to facilitate lay participation in care but also to develop colleagues professionally. Any change in practice is likely to require an educational input and if health professionals find it hard to educate each other then change, especially that which involves the education of patients and their family and friends, is likely to be hindered.

For true participation in care to become more than social rhetoric, a radical change in the health service is needed. Policy makers must be clear whether lay participation in care is to be founded on humanistic health promotion or bureaucratic cost effectiveness. Lack of clarity in relation to the underlying philosophy and politics leaves the government vulnerable to the accusation that lay participation in care is being used to "paper over the cracks" of a crumbling welfare state. It would appear that unless health professionals share common values and principles of lay participation not only with each other, but with the lay public and policy makers as well, then radical change, needed in the health service, will not be achieved. The findings from the study thus raise important issues which should be of concern to policy makers who are currently trying to change health professionals' perspectives to include notions of consumerism, partnership and lay participation in care.

Whilst professional ignorance, fear of a conspiracy and inadequate preparation for practice are likely to have been important factors in the failure to achieve significant change in the present study, evidence suggests a variety of other factors also acted as barriers to change. These factors are not necessarily related to lay participation in care and it is argued that they would have impeded other attempts at innovation. Much change is being imposed on health care practice and therefore these findings may be of

interest to practitioners and policy makers alike. It is argued that hospitals need to foster and develop cultures more conducive to change.

LACK OF CHANGE IN PRACTICE: SEEKING SOME PLAUSIBLE EXPLANATIONS

Whilst the health professionals' perceptions of lay participation in care clearly influenced the lack of change reported in the study, other findings highlight the need to create cultures in hospitals which are more supportive of change. It is argued that whatever the nature of the proposed change, it is unlikely to have been successful given the cultural environment at that time. Overall participants in the study were more anxious to maintain the status quo than investing time and energy in changing practice. Plausible explanations for this include the health professionals' reluctance to change routinised patterns of work, lack of enthusiastic leadership, lack of a supportive culture, lack of time, energy and resources and the transient nature of the workforce. It is argued that these factors remain prevalent in other wards and in other hospitals and therefore raise important issues which may be of concern to those wishing to foster change in hospital practice. The need to challenge the status quo and overcome barriers to change has been identified elsewhere in the literature (Dingwall et al., 1988).

Reluctance to change routinised work patterns

First it was suggested that professionals were reluctant to change their practice on account of being locked into routines and patterns of work. Some senior professionals were perceived by other participants to be in a long established rut and other more junior staff claimed to be clinging on to tasks to cope with the uncertainty of their newly created roles. The literature suggests that health professionals cling to routine tasks as a social defence mechanism against high levels of anxiety and stress caused by the awareness of human suffering in the professional-patient relationship (Menzies, 1988). Similarly it could be argued that lay participation in care is particularly threatening to health professionals as it requires them to form close relationships with their clients. Routine and ritual practice can also be seen as a way of redistributing responsibility (Menzies, 1988) and again this may be the reason why junior members of the team were reluctant to change. However, it is also important to understand ritual practices as social acts as well as psycho-dynamic responses to a situation (Chapman, 1983). This approach to understanding might best explain the behaviour of the more senior staff who were thought by other participants to be "in a rut".

It could be also argued that reluctance to change is part of an adaptive process in which participants show concern at being seen to undermine the validity of past systems

(Robinson, 1991). Robinson draws on the work of Marris (1984) and suggests that resistance strategies may well function to control the tide of change while the profession collectively takes time to re-assess the system by which it makes sense of its practices, values and beliefs. She suggests that resistance to change is not indicative of professional intransigence but rather an incomplete process of adaptation which should be viewed positively rather than negatively (Robinson, 1991). This adaptive process, whilst psychological in nature, can also be seen as a social act concerned with generating and conveying social meaning. Chapman (1983) stresses the importance of appreciating the sociological as well as the psychological explanations of ritual and rational actions in hospitals, in order not only to explain but also to change them.

In the present study reluctance to change practice was also associated with how staff viewed their work. Some participants saw work as a "job to be done" whilst others felt more committed to the professional development of nursing. Previous researchers have identified differences in nurses' attitudes towards work and grouped respondents as perceiving nursing as "Nursing, come what may", "Nursing, but for how much longer", "Nursing, battling it out" and "Nursing, just a job" (Francis et al., 1988). Those belonging to the category "Nursing, just a job", lay emphasis on their readiness to leave for personal reasons and are less concerned about the career and professional developments within the job. Whilst clearly there may be many understandable and good reasons why nurses identify with this group, participants in the present study suggested that nurses who saw work as "a job to be done" were less likely to be willing to invest their time and energy in changing practice. This is in contrast to other research which suggests that nurses falling into this category actually have a deep investment in nursing being more than just a job and are keen to destroy the myth in our culture that nursing expresses what is regarded as the female capacity to care, cherish, love, give and serve (Williams et al., 1991). Williams (1991) argues that nurses' attitudes are dynamic and can change throughout their career trajectories. Nonetheless the possible effect of these attitudes on their behaviour needs to be acknowledged. Rather than placing blame on nurses (or other health professionals) it is perhaps best to recognise that these attitudes can act as barriers to change and attempt to address their cause instead.

Reluctance to change was thought to be further compounded by professional conservatism created through fear of litigation and also the perception that lay participation in care was a threat to professional practice. It would appear that no research has been done on health professionals' fears of litigation but the study suggests such fears may get in the way of health professionals feeling able to respond to change. It may indeed feel safer for health professionals to maintain the status quo rather than take

personal risks in engaging with new ideas. This issue clearly has implications for policy makers who need to consider how best to create a "safe environment" in which changes in practice might be developed.

Professional conservatism seems also to centre around change being a perceived threat to professional practice. It is argued that over time health professionals have developed considerable power and it is suggested that they are unlikely to wish to relinquish this power unless there is to be some personal gain. Any change, and in particular one that involves lay people becoming more involved in care, is likely to affect the balance of power and as such is seen to be threatening by some professionals.

Sociologists have analysed the power held by medicine (Parsons, 1950; Freidson, 1970; Freidson, 1970a; Zola, 1972; Starr, 1982) and more recently it has been examined in the light of the newly acquired power held by nurses (May, 1992). It is suggested that since the early nineteen sixties there has been the emergence of a powerful professionalising movement in nursing (Dingwall et al., 1988), the focus of which has been on "individualising" patient care (May, 1992). It is argued that there have been unintended consequences of this development which impinge on professional power. First, it is suggested that nurses, by focusing on patients as individuals, have attempted to displace the traditional impersonal bureaucratic encounters between patients and health professionals. Second, by attempting to reveal the underlying reality of the patient's experience, nurses have extended the medical profession's "clinical gaze" (Foucault, 1973) to a "therapeutic gaze" under the auspices of nursing. It is argued that this shift to subjectify the patient not only offers a powerful set of ideas which gives more value and meaning to nurses' work, but also alters the balance of power in their relationships with patients. It is suggested that although the power to define and respond to the patient as an individual rests with the nurse, it also requires negotiation and legitimation with the patient. Thus whilst this added dimension to the nurse's role could be seen as yet another dimension of the "imperialism" thesis outlined in radical critiques of medical knowledge and practice since the 1960's (Illich, 1976), the subjectification of patients could also be viewed as a new locus of power for nurses (May, 1992). Either way lay participation in care, which emphasises the individuality of patients and encourages more equal partnership, could be seen as a threat to traditional professional practice in the way in which it changes the power dynamics both in the lay-professional and professional-professional relationships.

Thus it is argued that the reasons for health professionals being reluctant to change their practice are varied. This thesis takes an eclectic approach to understanding

phenomena and recognises the importance of both sociological and psychological explanations in understanding resistance to change.

Lack of enthusiastic leadership

A key issue identified by participants was the lack of enthusiastic leadership in managing change in practice. Participants believed that the charge nurse had a central role in initiating change. The importance of the charge nurse in managing nursing and the influence on individualised patient care has long been recognised (Pembrey, 1980). However, it is argued that traditionally leaders have used characteristics such as authority, control, competition and logic, alongside approaches which have been autocratic, directive and task oriented (Davidhizar, 1993). This is not surprising given that nursing has its roots in the military and ecclesiastical orders (Dingwall et al., 1988). However, it is suggested that as the values of society change and focus more on human needs, health care employees, as well as those in business and industry, are downshifting and electing to work in occupations that are more personally fulfilling. The present study demonstrates the authoritarian management style of the original charge nurse and how it was clearly contrary to supporting the development of creative change on the ward. Participants expressed a strong desire to address the management practices on the ward and identified the need for a more dynamic leader who was more person centred and professionally committed. Davidhizar (1993) discusses the need for charismatic leadership in the health care environment in order to respond to unrest and dissatisfaction and promote a new optimism. Drawing on the work of Barker (1991) he describes an emerging paradigm that is revolutionising modern management, namely *transformational* leadership. According to Barker (1991) the new transformational paradigm is characterised by mutuality and affiliation, acknowledging complexity and ambiguity, co-operation versus competition, an emphasis on human relations, process versus task, acceptance of feelings, networking versus hierarchy, and recognition of intuition.

This kind of charismatic leadership stems from Weber's (1947a) views on different types of authority which underpin various theories of organisation. Later in this thesis these different theories to advance the need for a new type of culture within health care practice more appropriate to the society in which we live are explored. It is possible that the new charge nurse in the present study was a charismatic transformational leader. However, it is interesting that even this style of leadership did not bring about immediate positive change because other factors influenced the impact she was trying to make on practice. Whilst research into the role of the charge nurse has identified him/her to have a critical role in determining the atmosphere of the ward (Revans, 1964; Lelean, 1973; Orton, 1981; Fretwell, 1982; Ogier, 1982; Reid, 1985), there is also a body of research

demonstrating that external constraints can impinge on leadership behaviour, resulting in a task oriented or directive style of leadership (Goldenberg, 1990). The present study has uncovered some of the constraints encountered in clinical practice which led to the maintenance of task oriented practice rather than facilitating patient centred care.

It is interesting to note that all groups of health professionals identified a lack of enthusiastic leadership as being a major barrier to change. However, whilst junior colleagues commented on the lack of enthusiastic leadership from within their disciplines, more senior colleagues absolved themselves of responsibility for managing the change and perceived it to be the charge nurse's role only. This aspect of the charge nurse's role appeared to be covert and as already discussed the power dynamics on the ward meant that she was not always able to influence change. So whilst the literature identifies the charge nurse as a powerful "professional gatekeeper" who has enormous potential to influence change for better or worse, not all charge nurses are like minded in their commitment to new developments in patient care (Beardshaw and Robinson, 1990a). For this reason Lewis (1990) suggests that future developments in patient care depend on change within charge nurses. It is argued, therefore, that in the future careful attention needs to be given to the selection of charge nurses to ensure that they possess the qualities of dynamic leadership to initiate and direct change. Furthermore if change is to be managed properly there is also an urgent need for professional development of charge nurses already in post who are not perceived to be dynamic leaders. Alternatively consideration needs to be given to redirecting them into less influential roles, otherwise, as Lewis (1990) noted, because of their position of power, these charge nurses may negate efforts to bring about change into patient care. It is hoped that by being proactive in developing practice and acting as confident assertive practitioners charge nurses will be able to make use of their powerful position to influence others and break through some of the barriers to change in order to facilitate new modes of patient care considered more appropriate for modern society.

Clearly in the present study some senior members of the multidisciplinary team were ignoring their responsibility to develop professionally and manage their staff. For instance, junior medical staff received little or no orientation to the ward and were very much left to their own devices in their day to day work and as a result probably hid behind routine tasks to reduce the stress and uncertainty in their practice. Whilst this issue is clearly related to a lack of enthusiastic leadership, it can also be seen to be related to a lack of management systems to support and develop staff in their changing roles. Similarly senior nurses did not appear to have the educative, supportive and supervisory skills required to act as competent co-ordinators of the key nurse system. It is ironic that

the management skills required to develop the professional skills necessary to facilitate change in practice, appeared to be lacking. It is even more ironic that these are the same skills needed to foster lay participation in care with patients. Therefore it is argued that there is a need for a different type of health professional able to work more as a facilitator and less as an authoritarian director, if practice is to change. Hegyvary (1982) has suggested that as nurses move towards new methods of working which emphasise individualised patient care, a professional model of work is required in contrast to the assembly line model normally associated with task allocation. However, Douglas and Bevis (1983) and McLure (1984) report that often external constraints impinge upon leadership behaviour, resulting in task oriented or directive style leadership style.

It would seem, therefore, that new approaches to health care require different forms of management. Duffield (1991), in a review of the literature on first-line managers describes how the role has changed in response to an increasingly complex environment where decentralisation and cost effectiveness have become key issues. Drawing on the work of Peters and Waterman (1982), she identifies decentralisation as having a profound impact on the role and function of managers which requires them to develop new skills such as participative decision making, the use of motivational techniques and greater emphasis on group skills rather than controlling functions (Powers, 1986). Duffield (1991) suggests the effects of decentralisation are similar to the effects of introducing primary nursing, namely, an increase in job satisfaction (Branson, 1981) a decrease in staff turnover (Munschauer, 1983) well motivated staff who strive to improve cost-effectiveness and quality of patient care (Kroeber, 1986) and an increase in decision-making (Powers, 1984).

Duffield (1991) suggests that the change of role from clinician to manager can result in role confusion and conflict. Findings from the present study suggest that not only is such a change in role essential to facilitate lay participation in care but also to foster any change in practice. Furthermore it is argued that the change in managerial role is not only an issue for nurses but also for medics and paramedics alike. It is clearly inappropriate for senior medics to rely on the charge nurse to be responsible for leading change when usually they hold the power base. Health care professionals need to work more closely together to facilitate change, sharing not only philosophical understandings of health care practice but also having greater awareness of management styles and strategies for change.

It would appear that compared to other professions nurses have taken the lead in recognising the need for change and preparing themselves for it (United Kingdom Central

Council for Nursing, 1986; Larcombe and Maggs, 1991). Yet interestingly nurses have been marginalised, not only by themselves but by general managers and politicians. Nursing has been described as the black hole of formal health care with those on the outside, unable (or not wanting) to see in and those on the inside unable (or not wanting) to see in or out (Strong and Robinson, 1988). Following the internal reorganisation of the NHS initiated by the Griffiths Report (1983) the relative managerial unimportance of nursing became apparent (Strong and Robinson, 1988). Owens and Glennerster (1990) perceived this to be, in part, an issue of gender, arguing that to some extent nurses' relationships with medics had been conditioned by the sexual division of labour, which in the past was a nurse/female and doctor/male dyad.

Lack of a supportive culture

The need to provide nurses and other health professionals with a supportive culture in their endeavour to foster better interprofessional work to challenge the status quo is argued in this thesis. Earlier in this chapter, good multidisciplinary teamwork was identified as a key factor in facilitating lay participation in care. However, it is clearly an important factor in achieving any change in health care practice. The present study found that not only was multidisciplinary teamwork poor in terms of interprofessional communication, but even within disciplines there was a perceived lack of concern and support for the individual.

Health care is frequently acknowledged to be a stressful occupation (Menzies, 1960; Bailey, 1985; Plant et al., 1992). A number of large-scale studies have shown that work related stress is more common amongst nurses than many other occupational groups (Parkes, 1980) and could be one of the reasons for absenteeism (Clark and Redfern, 1978; Cooper et al., 1988). Llewelyn (1984) identifies the types of stresses encountered in health care as including emotional reactions to patients' illnesses (sometimes repressed), fear of doing something wrong, responsibility without adequate training or support, empathy with the suffering of others, social isolation, lack of awareness and devaluation of roles, medical and male domination, conflicting values and standards of care and a tendency not to be able to separate professional and personal life easily. Yet despite these stresses health care professionals do not appear to offer each other supportive relationships to buffer such difficulties.

Lack of a supportive culture in the present study was related to the project taking place at a time of great stress, burnout, the key role of the charge nurse and lack of time, energy, resources and low morale.

A time of great stress

This study took place not long after the implementation of the Griffith's Report (1983). Owens and Glennerster (1990) suggest that during this time there was an attempt to delegate more responsibility to charge nurses. However, the report was published precisely when demographic changes had resulted in greater demands being placed on the Health Service and also at a time of increasing economic stringency. Changes in society and advances in medical science had led to different expectations and the demands of an increasingly dependent ageing population had put a strain on nurses working at the forefront of the service. Furthermore, Owens and Glennerster (1990) identify that there had been deep-seated conflicts within nursing which included conflicts between union and professional values, the nature of education and training, the structure of the profession and issues of power within the Health Service. At that time there was also considerable industrial unrest which was related to pay and the perceived value of nurses in society. Griffiths was seen to disrupt nursing leadership and professional support. There was a period of great uncertainty with nurses, at all levels, adjusting to new roles and responsibilities. The traditional hierarchical nature of nursing meant that managers were less well-adapted to respond to the new pressures. In particular middle managers were placed under tremendous pressure to meet unfamiliar financial goals and were given even greater workloads. Not surprisingly the changes resulted in crisis management and a gulf developed between middle managers and charge nurses. Middle managers appeared to be overburdened with routine functional tasks and offered little positive support or praise to their colleagues.

The present study participants (at all levels) complained about the lack of support. Whilst they found it hard to articulate what they meant by lack of support, they clearly felt unsupported, not only in their traditional roles but also in their endeavours to change practice. They suggested that issues were often swept under the carpet and that senior staff appeared to lack the managerial skills to cope with change. This was also found by Owens and Glennerster (1990) who, in a three year study of nurse management in one Regional Health Authority in 1985-1988, identified a lack of communication and responsiveness from middle management, plus the feeling they had no control or capacity to change anything. They also suggested that most of the irritations of ward management were off-loaded onto middle managers, who at that time were the interface dealing with staff shortages on wards, inadequacies of support services and budget overspends.

Burnout

Lack of support from management and colleagues was thought to be part of the reason why some participants experienced "burnout" and felt unable to cope with new ideas.

"Burnout" has been described as:

> *'a depletion of energy, in which personal resources seem to be at an end, leaving a continuing sense of helplessness and negativism in the face of normal everyday events."*
> (Brockman, 1978; cited in Dolan, 1987)

Several staff, and in particular the original charge nurse, complained of "burnout" and feeling exhausted. There was a sense in which individuals were finding it hard to cope with aspects of their work and yet there was no mechanism to deal with it. In the literature burnout would appear to be significantly associated with hopelessness and loss of idealism with work (Pines et al., 1981). In the present study it appeared to be associated with lack of support and resulted in feelings of powerlessness and inter-staff conflict. This finding is supported by Mackay (1989) who in a study of seven hundred nurses identified lack of support from colleagues and failures in communication (together with a system which was unsympathetic to the problems of individuals) to be important issues related to wastage amongst nurses. In Mackay's study, which looked at issues related to nurse recruitment and wastage, nurses frequently referred to "bitchiness" in the work setting, thus supporting the idea that many nurses have adopted misogynist attitudes. The study also highlights the issue of gender, as Mackay argues that nurses tend to adopt subservient attitudes which result in the norm of muttering about discontents rather than assertive action (Mackay, 1989). Whilst in the present study participants did not refer to "bitchiness", there was evidence of inter-staff conflict and lack of support at all levels.

Burnout is inversely associated with job satisfaction (Pines and Kanner, 1982). There is also thought to be a positive relationship between job satisfaction and job involvement (Rabinowitz and Hall, 1977). However, it is suggested that a person who is highly involved in his/her job is more likely to feel extremely satisfied or extremely dissatisfied with it whilst an uninvolved person would experience less extreme reactions (Dolan, 1987). This issue should be born in mind by policy makers. Change of any description requires extra involvement by workers and whilst it is likely that this will lead to higher levels of job satisfaction, it can also increase the risk of burnout. Given that

different work environments can significantly affect the burnout rates within organisations (Pines et al., 1981), policy makers need to pay closer attention to the creation of positive environments for change before attempting to impose new ideas. Once again this reinforces the important role of the charge nurse as an enthusiastic leader but also supports the need for a supportive environment within which he/she can work.

Key role of charge nurse

Smith (1992) found that the ward atmosphere and social relations on the ward were largely determined by the charge nurse. She suggests that those charge nurses who express a commitment to a person centred philosophy (such as the nursing process) are more likely to create infrastructures which allow the production and reproduction of "emotional labour" in their wards. Emotional labour is described as the induction or suppression of feeling in order to sustain an outward appearance that produces in others a sense of being cared for in a convivial safe place (Hochschild, 1983). In the same way as emotional labour is sometimes avoided with patients (James, 1986), it also appears to be avoided with colleagues. Interestingly the findings from the study confirm those reported by Smith (1992) which link the atmosphere on the ward to the leadership style of the charge nurse. In the present study the original charge nurse did not express a commitment to patient centred care and clearly also did not produce an infrastructure to cope with emotional labour on her ward. As a result staff found aspects of their work difficult to cope with. This finding once again points to the importance of ensuring charge nurses are adequately prepared for their roles and able to cope with changing their practice to foster more patient centred approaches to care. It also stresses the damage that can occur if charge nurses fail to develop in this way.

Whilst Owens and Glennerster (1990) suggest optimistically that nurses are now better placed to develop their managerial skills more positively, the present study demonstrates the importance of creating positive environments when introducing change. Thus new and more flexible styles of management are urgently needed in the health service, with more democratic approaches not only related to care but also related to interprofessional relations.

Lack of time, energy, resources and low morale

Whilst clearly there is a need to develop more supportive cultures in which health professionals can develop and foster change, other factors which mitigated against the introduction of lay participation in care included the lack of time, energy, resources and low morale.

A review of the literature suggests that "lack of time" is frequently cited as a factor inhibiting nurses' ability to develop health education roles and it is often associated with a heavy workload and inadequate staffing levels (Wilson-Barnett and Latter, 1993). Field notes of the present study similarly record lack of time as being an important inhibiting factor in planning for change. Meetings were frequently cancelled or hurried to such an extent that it was difficult for participants to engage in any meaningful discussions. Interestingly the new charge nurse spent much of her own time to initiate change and on several occasions participants requested that research interviews took place in their own time because they were unable to leave the demands of their work. Participants also complained of inadequate staffing levels, support services and resources due to NHS cutbacks and also complained of feeling guilty because they could not deliver the standard of care patients deserved.

Time has been identified by Horobin and McIntosh (1983) as a social construct. They argue that common sense recognition of how the meanings of time vary across contexts contrasts with other common sense understanding of time as an objective, uncontrollable force to which we must adapt. They suggest that the work patterns of the hospital do not fit neatly into standard stretches of calendar and clock time as duty periods have to be staggered in order to maintain continuity. Furthermore they suggest that, whilst nursing tasks are transferable (and therefore more amenable to time), medical responsibility is not so easily delegated. In this way time is seen to be socially constructed around the task. However, it could be argued that, as nurses move towards new styles of nursing (Beardshaw and Robinson, 1990b; Salvage, 1992) which emphasise more the nurses' role and responsibility in individualised patient care, nurses' perception of time may be altering. However, not all nurses are moving towards these new styles of nursing and so divergent views on time may be held. Gibbs et al. (1991) make a similar point by drawing on the work of White (1985) who identifies a form of pluralism in nursing composed of three main subgroups ("generalist", "professionalist" and "nurse manager"). They suggest that these different groups are likely to hold divergent views on a variety of issues such as skill mix, staff turnover, staff and skill substitution, support workers, standards of care and quality of care and argue that these issues are complex and often highly political. The social construction of time around the task may account in part for the "lack of time" reported in the present study. Given that participants had traditionally been task oriented in their work and that lay participation in care required them to adopt a more patient centred focus to care, their perception of time may have been challenged.

However, other factors such as the older and more frail inpatient population which requires more skilled nursing care, plus higher patient turnover, constraints on the supply of skilled nurses and continuing pressure on resources, are probably as important in understanding the health professionals' perception of lack of time. Furthermore it would appear that as the demands for health care have increased, staffing establishments have remained fixed. Maynard (1987) suggests that nursing establishments have been more determined by rhetoric, historical accident and well intentioned guess work than by scientific evaluation of the needs of the individual patient. The Audit Commission (1991), responsible for the external audit of the National Health Service in October 1990, recommended a need for more large-scale research into nursing outcomes in respect of how they are affected both by the number and mix of the ward staff and by the changes in nursing practice and organisation of care. They acknowledged that problems existed in changing nurse establishments and identified that nurses were carrying out inappropriate duties. Furthermore they found that nurses were not being used well in relation to patient needs and highlighted inappropriate mismatches between workload and staff.

Clearly there is an urgent need to properly assess the number and mix of ward staff required not only to take account of the changing demands of day to day work, but also to take account of the current radical changes in health care. Health professionals need time, resources and support to feel able to share ideas, develop common understandings and be able to work more purposefully towards change. They should not feel under pressure to use their off-duty time nor should the need for such discussions be allowed to compromise patient care. Without the time for policy development lay participation in care will remain at the level of rhetoric and the traditional methods of care will continue which may be out of step with the rest of society.

In the present study the lack of time needed to initiate change was created by staff shortages and increased work load. This in turn affected the morale on the ward which participants perceived to be very low. Factors giving rise to such feelings included dissatisfaction with the poor physical work environment, uncertainty created by constant change within the health service, feelings of job insecurity due to financial cutbacks and job dissatisfaction created by imposed redefinition of roles and responsibilities.

Low morale has been associated with inadequate levels of funding of the health service, staff shortages and declining standards (RCN, 1984). At ward level Ersser and Tutton (1991b) suggest there are numerous sources of dissatisfaction including inadequate preparation for new roles (Lathlean et al., 1986), the challenge of working

both as a skilled practitioner and as a ward manager (Binnie, 1988) and a lack of confidence in their management ability (Vaughan, 1980).

Mackay (1989) found that the standard of nursing care seemed to be falling on account of too much work being expected from too few staff. She argues that pay levels, lack of training opportunities, promotion, child care and flexible hours give an impression of a workforce that might easily be replaced and suggests there is also a failure to develop nurses and maximise their potential. She believes that understaffing leads to a reliance on tasks which frustrates the nurse who is more comfortable with more individualised patient care and which has been shown to be linked to greater job satisfaction (Sellick, 1983; Reed, 1988). Furthermore Mackay (1989) found there to be an over reliance on quantity as opposed to quality of care and argues that the search for professional status by some nurses could be in response to this. On the other hand she found some nurses to be "anti-academic" and colluding in maintaining the traditional subservient attitude towards the medical profession. These powerful gender issues identify nurses as being their own worst enemy at times and are clearly associated with feelings of low morale.

Low morale is thus seen as a significant barrier to changes proposed in the present study.

Transience in the workforce

Another, and perhaps final explanation of the lack of change when implementing lay participation in care is the transient nature of the work force. In the present study transience was seen to be a major barrier to change by all groups of participants and in particular medics and paramedics. Being a London teaching hospital, participants were often allocated to work on the ward for only short periods of time (frequently as little as three months). This issue of transience made it impossible to establish a cohesive work force to change practice. Typically, participants would start work on the ward and not be interested in developing new ideas as they would not be on the ward long enough to reap the benefit. They often struggled to adjust to their new roles and did not appear to have the time or energy to consider new ways of giving care. As a result they tended to give care in a task oriented manner.

Procter (1989), with reference to learner nurses, suggests that nursing routines provide qualified nurses with a method for maintaining control, stability and accountability for the care being given by a transient workforce. She argues that if as a profession, nursing wishes to reduce dependence on ward routines as a method of organising care (and so reduce the iatrogenic consequences identified as resulting from

these routines), then it appears necessary to reduce dependence on the transient workforce (including learner nurses) in the staffing establishment of training wards. It is argued therefore that the issue of transience is not only a problem with learner nurses but also with other members of the multidisciplinary team. Clearly innovative approaches to care will not be adopted when such care differs from that which is given on other hospital wards. This has wide implications for introducing change in hospital settings. Either there needs to be less reliance on a transient workforce or change should be introduced uniformly throughout the hospital setting at a given time. This would require intensive reorientation of staff to new methods of work and high levels of interprofessional collaboration. For change to be successfully implemented manpower planning cannot think solely in terms of requisite numbers for practice. Consideration also needs to be given to length of allocation for any one health professional to foster meaningful multidisciplinary relationships and understandings.

It could also be argued that transience leads to the same negative consequences of general staff turnover. Whether a health care professional leaves a ward as part of a centrally organised planned process or is making a deliberate career move, it can still count as a disruption to ward practice. Nursing has traditionally been a high intake, high wastage profession (Audit Commission, 1991) and has been the subject of a large number of investigations (Cavanagh, 1989). The loss and disruption of organisational performance is seen to be a major consequence of turnover. It is recognised that there is loss of efficiency on the part of the leaver prior to the separation (Cavanagh, 1989) and the effect of this on other team members in terms of added work and stress has been documented (Mobley, 1982). Furthermore turnover is thought to have an effect on group cohesiveness, performance and morale (Price, 1977). In terms of effect on patients, there is some evidence to suggest that turnover can have a detrimental psychological effect (Phillips, 1987), decrease the quality of patient care (Stryker, 1981) and is associated with longer stay in hospital (Revans, 1964). Further research is required to determine whether transience within hospitals produces the same issues as general turnover of staff. There does not appear to be research into this aspect of hospital life but it is argued that transience is, nonetheless, a major barrier to change.

ROLE CULTURE AS IMPEDIMENT

Thus it is argued that there are a variety of factors which can impede the implementation of lay participation in care. In a study looking at change it is easy to blame individuals for their lack of understanding or willingness to change practice. However, by looking at the findings in their local and historical context, as well as in

relation to the research based literature, it is possible to better understand the constraints on the participants' actions.

Having identified the practical influences and barriers to change, a theoretical explanation arising from the literature on organisational change will be explored. It should be noted that the issues and problems described in this thesis were raised by participants and were fed back for confirmation and exploration throughout the study. However, it has not been possible to share the final report with them. Since the time of the study, the ward has undergone considerable change and there is only one participant with whom contact has been maintained. Therefore this thesis represents a personal account and my interpretation of events.

Generative action research takes an eclectic approach to research and recognises not only the need for explanatory adequacy but also the need for theory with a generative capacity (McNiff, 1988). Throughout the study there has been an emphasis on being eclectic. It can be seen not only in the topic of enquiry, namely lay participation in care, (which questions reliance on professional care) but also in the chosen action research approach, use of mixed methods in data collection, discussion of findings in relation to a range of disciplines (social psychology, medical sociology and organisational theory) and finally in the use of theory to explain phenomena. By recognising the need for theory with a generative capacity, the view is taken that theory is an organic device to create other theories that may be applied in other settings. It is therefore my intention to explore the findings of the study in relation to organisational culture, taking account of the paradigm revolution in organisational theory (Lincoln, 1985) which again encourages eclecticism in developing a range of cultures in any one organisation to meet the different needs of different parts of that organisation. A dialectical view of rationality is taken (Carr and Kemmis, 1986) which recognises that there are "objective" constraints on social thought and action which are beyond the control of particular individuals or groups. Equally it recognises that there are "subjective" constraints which people could change if they were more aware of them. By relating the findings to organisational theory, I hope to enable practitioners and policy makers to consider ways in which practice might be encouraged to change in hospital settings in order to facilitate better approaches to patient care in a rapidly changing social world.

There is a growing literature on the culture of organisations (Handy, 1993); they are seen to have different values, norms and beliefs which are reflected in their different structures and systems. These different dimensions of an organisation reflect the essence of its culture and are affected by past events, present climate, type of work, general aims

and the kind of people working within an organisation (Handy, 1993). Harrison suggests that there are four main types of culture on which organisations are based: *power, role, task* and *person* (Harrison, 1972).

A power culture relies on a central power source influencing others to think in a like minded way. It depends on trust and empathy for its effectiveness and relies on personal conversation for communication. There are few rules and procedures and little bureaucracy in a power culture and a lot of faith is placed in individuals to achieve results.

According to Handy (1993), role culture works through logic and rationality, resting its strengths on its functions and specialities. Role cultures are largely controlled by procedures and rules and co-ordinated from the top by a narrow band of senior management. In this type of culture the individual is less important than the job required to be done. Position power predominates, personal power is discouraged and expert power only tolerated in its proper place. Role cultures offer security and predictability and allow the development of specialist expertise without risk. They reward the people doing their jobs up to a standard but frustrate those individuals who want more control over their work.

The task culture is job or project oriented. It seeks to bring together the appropriate resources, the right people at the right level of the organisation with the freedom to get on with the task. Influence is based more on expert power and is more widely dispersed within the organisation. It is a team culture which emphasises the need for individuals to work efficiently together to achieve the organisation's aims and objectives. Task culture can be likened to Burns and Stalker's organic system (Burns and Stalker, 1961). Given that "task" has acquired a pejorative note in health care settings, in this thesis the culture is referred to as "team" instead.

The person centred culture is the least commonly found in organisations. In this culture the individual is the central point and if any organisational structures exist, they do so merely to serve the individual. Control mechanisms and management hierarchies only function through mutual consent and with this culture the organisation is subordinate to the individual and depends on the individual for its existence.

It is suggested that organisations gradually change their dominant cultures over time (Handy, 1993). Most organisations start as power cultures being dependent on their founder member(s), but as time moves on, success leads to growth, specialisation and

formalisation within the organisation. This cultural change frequently marks a shift towards the development of role culture. However, it is argued that as an organisation grows, formalisation and specialisation are no longer sufficient to control the diversity of problems encountered and the organisation has to face the fact that it needs a range of cultures.

The data presented in this thesis support the case that hospitals have become locked in a culture that is outmoded, namely role culture. Role culture is often likened to Weber's (1947) "bureaucracy" and it is argued that Weberian assumptions have dominated the traditional or classical paradigm of organisational theory (Clark, 1985). However, more recently, a new paradigm has emerged which overthrows the rational bureaucratic model of organisations. New paradigm theorists argue that rationality rarely exists in practice and they place greater emphasis on complexity, ambiguity and difference. Organisations are not viewed as being monolithic, instead they are seen to be made of smaller segments which are responsive to and interactive with changing circumstance (Weick, 1985). According to Handy (1993), traditional classical management theorists have tended to emphasise role culture whereas modern management thinkers concentrate on team culture. Team culture is thought to be the culture most in tune with current ideologies of change and adaptation as well as individual freedom and low status differentials, although it is suggested that it should not be solely relied upon (Handy, 1993). Modern theorists suggest that in any one organisation there are different types of activity which need to supported by a range of cultures rather then one dominant paradigm. Handy (1993) identifies four types of organisational activity: *steady state, innovation, crisis* and *policy*. Steady state relates to all routine activity which maintains the infrastructure of an organisation and is best served by role culture. Innovation includes all activities directed at change and is thought to be best supported by team culture. Other activities such as crisis (which deals with the unexpected), and policy (which sets the overall guidance and direction of activities), are thought to be better served by power cultures. Person cultures are generally not thought to be of particular value in organisations as they to tend to focus on an individual's objectives rather than on the organisation's aims.

It is argued that hospitals appear to draw more from role culture than from team cultures and, as such, are ignoring the paradigm shifts in thinking which underpin modern management thinking. The existence of a role culture in the ward setting under study can be seen in the way in which the ward was described as being task oriented and lacking in multidisciplinary cohesion. Lay participation in care requires health professionals to be more patient centred, but one of the major barriers to change was the task oriented

practice on the ward. Senior staff tended to reinforce task oriented practice and as a result patients were not seen holistically. The Key Nurse system, which encouraged individualised care, also floundered. Ward staff found it hard to adopt new patient centred roles and found it easier to cling to the familiarity of tasks. They were locked in their traditional professional roles and were reluctant to divest themselves of such power, as this was seen to require more effort and perceived to be more threatening. Several health professionals described themselves as "just going to work to do a job" and were therefore not interested in the challenge of changing their practice. Whilst a team culture may have better facilitated change, relationships within the team would not support such an approach. For instance, within the multidisciplinary team there was poor communication, lack of role appreciation and medical dominance. Furthermore, within the team, some individuals appeared to have a preference for person culture and were thus disinterested in working collaboratively as team players, being more concerned with their own individual careers than the needs of the larger organisation. Interestingly the action research approach taken in the study brought with it new values which were more closely aligned with a team culture, for instance democratic forms of work, emphasis on individuality, teamwork and creativity. This new cultural approach to work was found to be too threatening for some individuals, who preferred to cling onto their "position power" in the hierarchy and work in a more controlled and predictable way. Thus the introduction of lay participation in care was seen as a radical change which not only required adjustments in the profession-patient or profession-client relationship but also required professionals to learn to participate more with each other. The enthusiastic leadership needed to generate the move from role to task culture was found to be lacking in those who had the authority to change practice. The leadership style was based on position power, which was more pertinent to role than team culture. Team culture would have required influence to have been more widespread within the team through the acknowledgement of "expert power". However, hierarchical practice and medical domination in the team prevented this from developing despite the efforts made through the action research process to foster more collaborative relationships.

Barriers to change not only focused on human factors but also organisational constraints. Findings suggest that the hospital environment itself was not conducive to supporting a team culture which would have fostered change more easily. Lack of manpower resources, made worse by the transient nature of the workforce meant that individuals were finding it difficult to cope with the routine work let alone thinking of new ways of changing their practice. Participants felt over stretched and unable to cope with change, there being no time for reflection and creative discussion. Lack of time or energy to cope with challenging practice was perceived by all groups to be the biggest

barrier to innovation. Several staff showed signs of "burnout" and a general low morale existed not only within the ward but also within the hospital itself. Thus the ward was not supported by the wider organisation in developing new practice. Furthermore, participants complained that they felt isolated and unsupported by hospital management, who in turn were bound up with their own concerns. Crisis management seemed to exist at all levels of the organisation and issues were swept under the carpet in order that the day to day functioning of the hospital might be maintained.

Thus it can be seen that the barriers to change identified in the study are all characteristics of role culture and that this appeared to be the dominant culture in the hospital. Attempts to foster new ways of working through the action research process based on team culture were thwarted by this dominant paradigm. New paradigm theorists believe that a variety of cultures should be supported in any one organisation to fulfil its different types of activities. Handy (1993) suggests that this differentiation of culture needs to be systematically integrated into the organisation and should not be left to chance. The study demonstrates what happens when integration of a different culture is left to chance.

This integration of different cultures in any one organisation is seen to be particularly important in situations where professionals are employed (Haralambos and Holborn, 1990). It is felt that professionals have a different type of authority based on expert knowledge which can be a challenge to those with bureaucratic power based on status within a hierarchical organisation. Weber (1947) has been criticised for failing to distinguish between bureaucratic and professional authority and for suggesting that an individual's position in the hierarchy is related to his or her technical expertise (Haralambos and Holborn, 1990). Given the degree of specialisation within society, highly qualified professionals are frequently required at lower ends of the organisational structure. Managers who are often higher in positional status are thus forced to seek advice from those of lower status in the chain of command. This has been found to create tension (Burns and Stalker, 1961) and dictates the need for other forms of control than the bureaucratic authority found in role cultures. Professionals are accustomed to autonomy, self-regulation and individual decision making and this conflicts with hierarchical control and the official rules of a bureaucratic administration. Such professionals need to be given the freedom to exercise their professional skill and expertise by channelling their professional motivation into the service needs of the organisation. The present study demonstrates that when health professionals work in a culture which does not allow their expertise to be acknowledged their potential for changing practice is stifled. Furthermore the medics dominated practice and the expertise of other health professionals was not

recognised. For change to be a reality in practice, team cultures need to be fostered and the issue of medical domination needs to be addressed urgently.

An eclectic approach is required in management which will allow for a variety of cultures to be developed in any one organisation. For instance, role culture might be needed to maintain systems within an organisation, but change might well depend on power cultures leading the way initially and team cultures allowing the development of ideas from within. Furthermore whilst person culture is not thought to work well within organisations, it must be allowed at times in health care practice to facilitate the professional development of individuals.

It is argued that until differentiation of culture within hospitals is supported, innovation is unlikely to succeed. Managers need to recognise the importance of allowing small segments within an organisation such as a ward to creatively develop their practice. They need to give positive encouragement by putting together the right people and the right resources so as to foster change and relax on the day to day control. Professionals need to be educated in modern organisational theory and recognise the importance of developing different cultures to achieve different tasks. This will require them to be more flexible and creative in their thinking and less hierarchical and more people oriented in their practice.

Whilst the study is concerned with lay participation in care, it is argued that the barriers identified in the study are likely to inhibit other forms of change. Within nursing radical change in practice is being advocated through the development of primary nursing (Department of Health Nursing Division, 1989). As a form of "new nursing" which emphasises individualised patient centred care (Beardshaw and Robinson, 1990a), it requires changes in traditional hierarchical systems of work (Webb, 1981) and focuses on humanising hospital care (Ersser and Tutton, 1991a). Primary nursing has been shown to create genuine change in the power relations of hospital wards (McMahon, 1990) and this change in culture appears to permeate the work of all grades of staff (Lincoln, 1985). It thus threatens the status quo in the same way as the introduction of lay participation in care (Meyer, 1993b) and other new approaches to nursing (Beardshaw and Robinson, 1990a). When compared with traditional systems, primary nursing is believed to result in a degree of higher quality nursing care (Bond et al., 1990), greater patient satisfaction (Sellick and Russell, 1983), improved job satisfaction of nurses (Giovannetti, 1980), be more cost effective (Marram, 1976) and to be worthy of implementation (Macdonald, 1988). The Government and advisors to policy makers appear to support verbally the developments in nursing which emphasise individualised patient care (Audit

Commission, 1991; Department of Health, 1992). However, unless policy makers create environments more conducive to supporting change, future developments in patient care might be thwarted and the inappropriate reliance on hierarchical nursing structures (routinisation, task oriented practice and a deference to doctors) will continue as an enduring occupational strategy (Davis, 1976; Davis, 1977). This will not be acceptable to patients who have clearly identified that they prefer to be cared for as individuals (Moores and Thompson, 1986) and would appear to benefit from nurses being more closely involved with them as individuals (Royal College of Surgeons, 1990). It is argued therefore that before imposing any change, policy makers should address more fundamental issues such as the need for cultural change in hospital settings. Until professionals can learn to work together as equal partners and hold common philosophical understandings and approaches to care, it is suggested that any innovation is likely to flounder.

Changes in health care are perhaps inevitable and past systems of work may no longer be appropriate. It is suggested that there has been a reliance on role culture within health care practice and that there is now a need to allow the growth and integration of different cultures which can respond to different needs as they arise. For instance, it is suggested that innovations should be nurtured and supported through the development of team cultures. The present study reinforces the important role of the charge nurse in managing change and illuminates the need for dynamic leaders who can motivate others and develop practice. For a variety of reasons health professionals may cling to task oriented practice but this is incompatible with new approaches to health care and organisational theory.

Findings from the study also raise questions about the morality of a government and policy makers who impose much change on health professionals at a time of low morale and economic stringency without first addressing whether the health care environments are conducive to such change. Such action is likely to add to the stress of health care professionals which in turn is likely to result in them clinging more to their routines and resisting change. Little is to be gained from such a short sighted approach. No doubt health professionals will merely continue to do as they did in the present study, that is, pay lip service to policy initiatives rather than translate the ideas into meaningful practice.

Whilst clearly these findings cannot be generalised to a wider population, it is hoped that by sharing the findings in sufficient contextual detail, others might feel in a position to judge their relevance to their own practice. Furthermore it is argued that many

of the findings are supported in the literature which might suggest that the situation encountered was not unique.

Drawing on theory at this stage of a thesis is perhaps unusual, however it is used only as a means of possible explanation for events that occurred in reality. It was intentional that theory should be applied retrospectively rather than prospectively in the study. It is recognised that although at times organisations attempt to be rational in the prospective sense, most often they are rational in the retrospective sense (Lincoln, 1985). Thus there is a tendency to act first and then analyse what was done later. As Weick (1985) argues intention seldom, if ever, controls action. However, because it is assumed that what appeared to happen did happen, then rational models are accepted as working when in reality they are not. It is argued that to use theory prospectively and prescriptively would have enforced a rigidity of design and purpose that would have denied the spontaneity and creativity of practice. In keeping with this the generative action research model espoused by McNiff (1988) was used in preference to the more structured models of Kemmis (1982), Ebbutt (1985) and Elliott (1991). By taking such an approach it was possible to explore problems as they arose naturally in practice without losing sight of the main focus of the enquiry. In the study it was possible therefore to explore such issues as ward organisation and multidisciplinary communication whilst at the same time being able to appreciate the impact that such problems might have on the implementation of lay participation in care.

CONCLUSION

This thesis argues that whilst current policy documents advocate lay participation in care, some health professionals are paying lip service only to the concept. It suggests that health professionals might be inadequately prepared to act as facilitators of lay participation in care and identifies the need not only for professional resocialisation but also re-education of the general public. It is argued that for true participation in care to become more than social rhetoric, a radical change in the health service is needed. The need for a different type of health professional capable of sharing knowledge with lay people through empowerment is advocated. In order to facilitate lay participation in care in practice, it is recognised that health professionals need to learn to participate more with each other by holding common philosophical understandings and approaches to patient care.

The current pervasive culture of acute hospitals appears to be one of "role culture" (Harrison, 1972) and it is argued that this approach is outmoded and inappropriate not only for facilitating lay participation in care but also for supporting any type of

innovation. The notion that no single culture should be allowed to swamp an organisation is supported (Handy, 1993). Given that "task culture" (Harrison, 1972) is most in tune with current ideologies of change and adaptation, there may be a need for this more flexible and creative approach to be nurtured in hospital settings. Furthermore the study findings suggest that policy makers could be criticised for imposing such change on health professionals at a time of low morale and economic stringency. Before organisational changes can be imposed, fundamental issues such as the need for cultural change must be addressed. Finally it is argued that until professionals can learn to work together as equal partners and hold common philosophical understandings and approaches to care, innovations in practice are likely to flounder.

Having argued the need to move beyond the rhetoric of lay participation in care and to create cultures more conducive to changing practice, the final chapter (Chapter 10) reflects upon some of the critical issues emerging from using action research as a methodology.

CHAPTER 10

ACTION RESEARCH: REFLECTIONS ON CRITICAL ISSUES

INTRODUCTION

Carr and Kemmis (1986) describe action research as a self reflective enquiry and emphasise the need to be reflexive. Action research is also recognised as being part of new paradigm research which has links with feminist scholarship (Callaway, 1981) and as such relies more heavily on the reflective and interpersonal skills of the inquirer and rejects positivist notions of rationality, objectivity and truth and instead acknowledges subjectivity, thus highlighting the need for self reflection. Berg and Smith (1988) suggest that the nature and quality of social research findings are powerfully influenced by the relationship between the researcher and the researched. They argue that this relationship should receive the same amount of scrutiny as other methodological issues in the research process and that any system of investigating social reality should address the whole research process. Therefore, this section of the thesis addresses the data obtained on the process of doing the research and attempts to make explicit the relationship between me and participants as well as highlighting issues that arose in the process of doing the study. It argues that action research has the potential to address sensitive issues and as such requires special consideration of the political, ethical and practical problems in carrying out this type of work.

RESEARCHING SENSITIVE TOPICS

Action research has dimensions which make its use in practice potentially threatening and as such is commensurate with researching sensitive topics (Renzetti and Lee, 1993, p.5). Renzetti and Lee define a sensitive topic as:

> *"a sensitive topic is one that potentially poses for those involved a substantial threat, the emergence of which renders problematic for the researcher and/or researched the collection, holding, and/or dissemination of research data."*
> (Renzetti and Lee, 1993, p.5)

Action research is often written in the format of case studies and thus individuals are more easily identifiable than in larger scale studies. This issue alone renders the nature of action research sensitive and raises the important issue of ownership of data. Action research is also concerned with changing practice and can be seen as potentially

threatening since it involves old systems of work being criticised and subsequently altered. Changing practice raises the sensitive issue of people with invested interests maintaining the status quo. It requires participants to work democratically and as such challenges the hierarchical relationships between participants. Action research is not merely concerned with changing practice but follows humanist philosophy which offers a way of being that might be alien to participants more used to working in authoritarian environments. Given that in action research, prescribed change is democratically decided upon, it cannot be known in advance of the study what that change might be and therefore participants cannot be said to be truly informed when they consent to participate in the research. Such issues make action research sensitive and as such are bound to have an effect on the relationship between the researcher and the researched. This highlights the need for open and honest relationships between the researcher and participants but also stresses the need for self reflection. Action research can be extremely stressful not only for the participants but also for the researcher. The stress centres on the tensions arising between the researcher and participants, for example the frustration of not being able to control the process of change and issues relating to the researcher's own self-doubts. In the past nursing action research studies have tended not to address the practical issues and dilemmas that make this work problematic. It is only more recently that the honest portrayal of some of the methodological dilemmas have been addressed (Meyer, 1993/1995; Webb, 1989).

This section of the thesis draws on data from the field notes and exit interviews which examine the issues encountered in the process of doing action research. Table 32 summarises the issues arising from the exit interviews and Table 32 outlines issues arising in the field notes;

Table 32: Comments on research process - main themes from exit interviews'

Comments on Research Process	N %	M %	P %	J %
Positive feelings towards researcher's input				
Enthusiasm needed. Acts as catalyst. Stimulating	40	40		31
Researcher gave new insights	30			12
Project viewed positively				
Project ideas good - wanted them to work	50			19
Charge nurse resented research				
Felt criticised - threatened by research	50			19
Saw it as an intrusion on her ward	40			15
Initially wanted project but changed mind	40			15
Research made her feel she was losing control	40			15
Took up too much time	40			15
Wrong environment for research				
Better with more dynamic leader and/or people	30			12

Table 33: Comments on research process - main themes from field notes'

ISSUES ENCOUNTERED DOING ACTION RESEARCH	
Acceptance of researcher	*In general* *By nurse managers* *By charge nurses* *By staff nurses* *By multidisciplinary team* *By medical staff*
Relationships between participants and action researcher need constant review	
Verbal support for research but no commitment	
Lack of ownership of research ideas inhibiting change	
Democratic forms of work create conflict	
Threatening issues raised in process of research	
Participants need confidence to work openly and democratically	
Sense of being manipulative	
Researcher self-doubts - working in isolation	
Research compromised by not being pre-planned	
Difficult to combine researcher role with practice role	
Difficult to withdraw from ward	
Benefits of action research	

From the above tables it can be seen that there are a variety of sensitive issues identified in the exit interviews and field notes. This section of the thesis begins by exploring my relationship with the participants and then moves on to explore some of the practical issues and dilemmas encountered in the process of doing the research.

RELATIONSHIP BETWEEN RESEARCHER AND PARTICIPANTS

From the outset I wanted to be viewed as an "insider researcher" (Simons, 1985) and deliberately chose to do the study in a hospital where I was known. I had worked in this hospital as a staff nurse in a variety of settings, and as a charge nurse on a general medical ward and as a nursing process co-ordinator. My role had involved facilitating change in practice throughout the hospital, before leaving to take up a career in teaching. Whilst I had not worked in the hospital for five years, there was a sense of going back to an environment with which I was very familiar. The value of being an "insider" centres around the researcher having a better understanding of the setting and being able to foster

more meaningful relationships with participants thus leading to more rich contextual data. It is believed that "insider" researchers have a greater chance of breaking through the value structures of privacy, territory and hierarchy and substituting the values of openness, shared critical responsibility and rational autonomy (Simons, 1985).

In my role as researcher I invested much time and energy in getting to know participants as individuals, making myself available to listen to their concerns and trying wherever possible to help them in their desires to change practice. I worked alongside them and went to their social functions as a member of the team. I endeavoured wherever possible to be an "insider" and to be a trusted and valued member of the team. The field notes record this process of acceptance but in April, after a few days absence from the ward, I write:

> *"I do feel I have gained acceptance as an 'insider' researcher. Within minutes the nurses were sharing their concerns and feelings for what had gone on in the previous week. Later the ward clerk recounted her own personal difficulties with family illness and the house officer had told me his girl friend problems! I seem to spend considerable time talking to everyone about their problems and whilst this is strictly speaking not research, I do feel it has helped me to gain acceptance on the ward. I also feel very concerned that my presence to gather data could be seen as very one sided and I wanted to give more of myself to even the balance. Everyone is working under stress and it seems immoral for me to add to that stress without consideration for other people's feelings. My acceptance as a nurse is also evident. Today X (staff nurse) asked me to help her put up some piped oxygen in the side room. There was no pretence that she knew what to do and she actively sought my advice. Once more I think this has helped my acceptance on the ward as another source of support. Perhaps this is why I find myself answering the phone when everyone seems too busy. It makes me feel I am "helping out" instead of being demanding of their time and energy all the time."*
> (Field Notes: R(F)p397/8)

By getting to know individuals in this way I believe that some participants felt closer and better able to trust me with their stories. I also felt that I was giving something to a relationship in which I sometimes felt I was the only one benefiting. The field notes record (refer Table 33) acceptance by all groups of professionals in both different ways and to different degrees.

General acceptance by participants

Initially I found that, in general, I was welcomed on the ward and participants appeared genuinely interested in the project ideas. In particular the initial interviews seemed to help me to develop closer relationships with participants and afterwards they would appear to have a better understanding of my role and included me more readily as a member of the team. By spending so much time on the ward and being readily available to listen, I found myself often in the role of counsellor and being privy to much confidential information. The nature of these conversations are not recorded in my field notes although at the time it seemed important to note that people did feel able to talk to me. This raised the issue of why participants appeared to be seeking support from a new member of the team.

Most of my time was spent in contact with the staff nurses and junior medics. As can be seen from Table 32, spontaneous comments on the research at exit interview suggest that the staff nurses most valued my input. The table illustrates that 40% of nurses and medics had positive feelings towards my input on the ward. They suggested that my enthusiasm was needed and acted as a catalyst for change. Some nurses found that I had given them new insights and many of the nurses felt positive about the project ideas, commenting that they wanted them to work in practice. At exit interview one nurse commented:

> *"Actually that was one of the things that I was talking about last night. I dread to think what the ward would have been like if you hadn't been there - because your presence, in the respect that you were able to give the staff direction that wasn't being given, by supporting them in their regular meetings and your ad hoc chats. I mean, I know, I can go back to a particular example where you said about the care plans we should be going around the wards, you know and discuss the care. Do you remember that? You were talking to X (staff nurse) at the time and you said 'Why don't you let them (the patients) tell you what should happen.' Now I didn't know any different until you pointed that out, you see. And likewise, although we had our flash points (misunderstandings) , as you might say, but when I went back and sort of thought about what you had said, I thought 'Right Julienne said this' and it began to sink in then. This is why I made the point at the meeting yesterday that we will miss our side-kick (the researcher)! It was nice at the time and the time that I worked with you, that when we just needed that little bit of reassurance and guidance, you were always there, and because I wasn't supported, I'd had to look elsewhere for support and I latched on to you, you see, which has helped me enormously."* (Nurse: N12(E)p16/17)

However, this supportive relationship whilst productive for some staff, was threatening for the original charge nurse.

Relationship with the original charge nurse

At her exit interview the original charge nurse explored both her relationship with me and the project. She said that the research had made her feel criticised in her work and this she resented. She had found the research to be an added pressure at a time when she was feeling already stressed and had found it to be extremely time consuming. She was conscious that everyone was talking about the ward to me, the researcher, and she found this confusing. She resented the fact that the research had become more concerned with how the ward was being run rather than lay participation in care and wished that I had taken a more subtle approach to changing practice. The original charge nurse felt I had relied too much on her to lead the changes and stated that she found motivating the staff nurses very difficult. In terms of my relationship with her, she felt that I should have led the change more:

> *"You should have organised us more. You put all your energy into writing and interviewing. People need spoon feeding - I didn't feel able - we needed more guidance"*
> (Nurse: N0(E)p15)

In contrast to herself, she found my enthusiasm difficult to relate to and said that on occasions it made her feel like withdrawing from the ward. She wished that I had been more able to recognise her stress because there were times when she couldn't cope with thinking about anything new. At exit interview she said:

> *"One Tuesday I felt I was going to burst, there was not room in my brain to think about anything else ..... but you didn't see it."*
> (Nurse: N0(E)p5)

She felt that I organised too many project meetings and resented the time taken for discussions on lay participation in care. At these meetings she found it hard to switch off from the general ward work:

> *"I can't switch off, therefore I can't concentrate on the meetings, I am sat there thinking about the man going for ultrasound ..... my mind is at a pitch, I just have to keep on going."* (Nurse: N0(E)p5)

She felt that I was to blame for the fact that too much time had been spent on trying to change the way the ward was organised. She still felt lay participation in care would be an important aspect of future care, provided that people (staff nurses and relatives) could be persuaded to put in the extra work needed to make it happen. She discussed aspects of her job with which she felt she had difficulties and recognised that in some areas she was not living up to what was expected by other colleagues She felt over stretched in her work and suggested she was just coming to work to do a job and go home. She likened herself to other nurses:

> *"They just do their job and go home. I think I do that. Otherwise you destroy yourself. It's a self defence mechanism. If you stretch something too far it won't stretch any more."*
> (Nurse: N0(E)p8)

Clearly she was someone who was not coping with the demands of work and found my presence on the ward threatening. She felt that initially I had given people too much to read and suggested that people had not been able to cope with the amount of information. As time had gone on, little had been achieved and she felt the staff had become apathetic and bored with the project. She felt she had not been given enough support on the ward to make the expected changes and commented that the regrading exercise had led to unrest on the ward and inter staff conflict. She suggested that the meetings had brought a democracy which had allowed power struggles and arguments amongst the staff. She commented that it was difficult to go from old ways of thinking to new ways of thinking and yet still manage to hold the reins. She felt herself losing control of the ward.

On reflection I recognise that she did need more support and help in leading the change but would argue that I felt she was not receptive to such offers of help. On a day to day basis I found her difficult to communicate with and generally not receptive when I tried to engage her in discussion. I realise now that she was possibly suffering from "burnout" and finding it hard to cope with most aspects of her work. I think she probably agreed to do the project because she knew she was under pressure to change her practice and develop along the current professional trends. I suspect that she realised she could not do this on her own and hoped that I would do it for her. It is interesting to note that when the post of junior charge nurse was discussed she suggested I applied for it. Whilst clearly my presence on the ward constituted a threat to her, she nonetheless valued some

aspects of my work and I do believe she benefited from the project by reassessing her situation and moving on to a job she felt better able to do.

Whilst the research might be seen as enabling the original charge nurse to sort out her feelings in relation to nursing and move on into an area in which she might flourish, I feel on reflection that I should have spent more time during the negotiation phase exploring with her the nature of the project and its possible outcomes. It was clear from what she said that she felt inadequately prepared to participate in the project:

> *"I didn't understand what you were trying to do - you didn't make it clear. It was a shock when you came on the ward and started looking at how it was run."*
> (Nurse: N0(E)p20)

The exit interviews suggest that some of the nurses thought that the original charge nurse resented the research and felt threatened and criticised by it. Whilst they thought initially she had wanted the project to take place on the ward, they suggested that for her it became intrusive, which led her to feel she was losing control of the ward. The nurses claimed that the original charge nurse found the project too time consuming and because of this some believed the ward to have been the wrong environment for the study, suggesting it would have been better done with a more dynamic leader and team. As one nurse commented, the original charge nurse seemed to resent the project on the ward and at times appeared to block ideas:

> *"She just didn't want to change the ward. She's very old fashioned, I think. she wasn't interested in it at all. She felt you were more interfering. You were bringing about change on the ward that she didn't want, she didn't like. Things like the patients doing their own stool chart, particular patients were perfectly capable of doing it but she didn't like it. You know, and we thought 'Well, isn't this what lay participation is?' But she didn't like it, she didn't want that. Even though they were being supervised, she still felt it was a nurse's role. She was all for the project but when it was actually going ahead, she kept stopping us in our tracks."*
> (Nurse: N1(E)p13)

This reluctance to change may well have stemmed from a fundamental difference in understanding between the original charge nurse and myself as to what is meant by lay participation in care. The original charge nurse appeared to see it as a wholly technical matter whereas I perceive it to be a philosophical approach to health care. As a

philosophical approach, lay participation in care could not be introduced as a matter of additional routine; instead it required participants to completely rethink their working practices. Such a radical change was clearly threatening to the original charge nurse who, when agreeing to participate in the study, had not anticipated the need for such a change.

From the original charge nurse's perspective, she had never claimed to be enthusiastic for the change. At her initial interview, whilst saying she was willing for the study to take place on her ward and recognising that she would have to change, she never demonstrated any real enthusiasm. The following interaction illustrates this point:

R *'Right, so overall do you feel the ward is ready for change?'*

N *'I think so, yes, but I'm not really sure, it's only I think so rather than I'm sure so.'*

R *'Can you say why it's ready to change?'*

N *'Because you're here ready to change it.'*

R *'Right. Any other reasons?'*

N *'I don't think so no, I mean you've come up with an idea and we're willing to have a go at it, but I ..... we'll see how it works out.'"*

(Nurse: N0(I)p5/6)

I was aware at the beginning of the study that the original charge nurse had a reputation for being reluctant to change and perhaps on reflection this was not the most suitable ward for a change project. I was perhaps too encouraged by the more positive responses of the rest of the staff and had naively thought that with the support of a one to one relationship, the original charge nurse might be enabled to develop her practice. Thus this study highlights the importance of having the full support of the team leader as opposed to the team members alone.

The senior management welcomed the decision to use the particular ward and felt that the research would be good for the multidisciplinary team. However, on reflection, I suspect that management agreed because they wanted to "use me" to bring about changes they had failed to produce previously. Given that, in part, the project led to the resignation of the original charge nurse, I am left with feelings of unease. The study

highlights the importance of exploring possible hidden agendas with participants during the negotiation phase.

Fortunately, whilst the relationship with the original charge nurse was problematic, my relationships with other participants were less intense and generally more constructive.

Relationships with the staff nurses

Overall I believe the staff nurses appreciated my contribution to the ward. They appeared to appreciate the difficulties of my role and on the whole wanted the project to succeed. It was this group of participants who gave me the most support. They recognised and valued my enthusiasm and often commented that they had learnt a lot from me as a role model. They saw the developments on the ward as being positive and were angry when the original charge nurse appeared to block them. As one staff nurse said:

N *"Well I used to get very angry - someone was coming along, bringing change for the good of the ward and the patients and she was stopping it. She was stopping it at every turn and I got angry and upset that she said you were interfering. That was quite upsetting; but she couldn't see the good you were doing. She wouldn't see it"*

R *"Given that she felt that I was interfering, do you think the research should have continued?"*

N *"Yes, because you were doing good and this is the future of nursing - primary nursing - especially when Project 2000 comes in, and patients these days should be more involved in care. They should know what is going on with their relatives. It's nursing of the future to me but she wanted to stick to the old fashioned nursing."*

(Nurse: N1(E)p15)

Whilst the staff nurses appreciated my enthusiasm and drive for change, they were aware that original charge nurse resented the fact that they were relating more positively to me than to her, thus leaving her with the belief that I was taking over her role. As one nurse said:

"No, I think your enthusiasm was brilliant. I think you taught us all a hell of a lot on that ward, but then in a way. ..... I don't know, especially at the beginning, I think you probably took over sister's. ..... like we all came to you with our problems and started to view you as the Sister of the ward, I think - which perhaps caused sister to feel unwanted. But then that was bound to happen when one person was enthusiastic and another person wasn't."
(Nurse: N5(E)p7)

Some staff nurses felt less positive about my role on the ward. These nurses tended to be the ones who were not interested in trying to change practice and were just coming to work to do a job. However, I never felt they were openly hostile towards me and, with the exception of one, were quite prepared to participate with providing data for the study.

As time went on and progress continued to be hampered, I believe all of us felt disillusioned and disconsolate. My field notes record how on occasions I actively avoided the ward. This was bound to affect my relationships with people but in respect of the staff nurses I always felt able to discuss the impact of the project on our feelings. However when given the opportunity to halt the project, the majority of staff nurses felt a strong commitment and wanted it to continue. Clearly it is important in this type of work to address openly the feelings of all participants, including the researcher, at regular intervals during the study. Change can be a very demanding process and participants need to recognise that they cannot always maintain the same levels of motivation.

Relationships with the nurse managers

The project occurred at a time when the nurse managers were occupied with the nurses' regrading exercise. Whilst the nurse managers were verbally supportive of the project and interested in being informed periodically as to what was happening, I had very little contact with them. However, I believe that my relationship with senior management was good. Sometimes I was given confidential information, not always relevant to the project, and I felt that they trusted and respected me. The fact that they wanted to continue the project after I left and, with this in mind, were prepared to appoint a new charge nurse led me to believe that they supported the project ideas. The fact that they wanted me to stay on the ward when I offered to withdraw also suggests they felt positive about my contribution. My field notes record such a conversation at this time:

"Later I returned to the hospital to report back to X (nurse manager). She was pleased that my supervisor wanted me to stay. She had discussed the matter with

X (another nurse manager) and they both felt the project should go ahead. She acknowledged that they had not really supported me enough and were sorry that I had got to the stage of thinking about leaving ..... they wanted me to stay and help this charge nurse ..... In the future the NHS was going to radically change. Ward charge nurses would have to hold their own budgets and if X (original charge nurse) couldn't cope with this job now it would be harder later. She said she respected the issues I had raised as a researcher and believed them to be true. These issues could not be ignored whether or not I stayed and they preferred that I stayed to help monitor and facilitate the change."
(Field Notes: R(F)p244/245)

Whilst my relationship with senior management was good, their lack of involvement in the project was clearly a problem. Change should not be attempted without firm commitment and regular involvement from senior management, otherwise some participants may feel their efforts are not valued sufficiently and this may lead to a lack of team cohesion. Furthermore lack of commitment by senior management may lead to their involvement in change only at times of crisis. Thus a distorted view of the situation may arise and lead to inappropriate decision making on their part.

Relationships with the medics

My relationship with the medics was more varied. I did not have much contact with one of the two consultants involved in the project. However, he was always very polite and supportive when we occasionally met to discuss the project and he appeared happy to let me attend his ward rounds. However, I do not feel he gave the project much thought and somehow I always felt a little distant from him. I had more contact with the other consultant, who again was polite and verbally supportive of the project. However, I suspect he never really understood the type of research I was undertaking and perhaps felt a little wary. I believe he valued the attempts I was making to improve the practice on the ward and recognised the need for change but perhaps did not regard my work as "proper research". I was a female nurse doing research and I felt myself being subjected to the same power games as the rest of the team. As my field notes illustrate:

"The ward round followed the usual hierarchical pattern. This consultant was authoritarian and charming but certainly beyond challenge. Between beds, general medical and hospital issues would be discussed. He announced that there was to be yet another meeting for AIDS patients. He now had to attend four to six different meetings to discuss the management of AIDS patients. He felt it was all clearly ridiculous. He added this new meeting was to be attended by nurses and a

lay person! The tone of his voice indicated his disapproval and suggested their input lacked value. He felt there were too many meetings in the hospital and nothing ever got done. Nurses were at most of the meetings and it was a complete waste of time. There was even a nurse on the medical research committee! I could not help myself suggesting there was another point of view that could be argued. He immediately dismissed this comment and me and looked angry at the mere suggestion. I felt the pressure to conform and let the issue lie. For the rest of the ward round I felt unable to contribute anything, very conscious that my words were ignored and that I was being placed to the outside of the team both physically and psychologically."
(Field Notes: R(F)p394/395)

My relationship with the other members of the medical team also varied. The junior house officers always seemed to "keep their distance" from me whilst they settled down on the ward. I think they were worried that I would give them something else to do and think about, concerning which they were perhaps not interested or able to cope. However, by the end of their three month allocation they appeared to relate well to me as a person and appreciate the changes being attempted. My relationship with the more senior medics was helped by their longer stay on the ward. Again I felt they related to me as a person and understood the need for the changes I was trying to facilitate. However, as with the consultants I did not feel they respected my position as a researcher. The following is a field note entry made at the end of the ward round in which I had been made to feel isolated within the team:

"Before the ward round dispersed, he (consultant) asked me how my research was going and if my supervisor was pleased with it so far. I said that the change was slow, but I was gathering a lot of data with which my supervisor was pleased, although concerned that I had too much. He suggested the study would be hard to write up and another colleague (senior medic) said it would be difficult to examine it. The ward round angered me but once more gave a good example of the power and autonomy given to the medical profession. Their scepticism and disregard for my comments and research only added fuel to my feelings of inadequacy."
(Field Notes: R(F)p395)

Whilst feeling criticised as a researcher by senior medics I did feel accepted by them socially. For the reasons outlined I believe the power dynamics on the ward had a

negative effect on the development of the research ideas and it is interesting to note, in time, that I too fell victim to them.

Action research requires participants to work together democratically. For some organisations this is not part of their normal practice. This study highlights the need to stress this point when negotiating access to a study site. Unless participants are prepared to work democratically, change is unlikely to flourish.

Relationships with the paramedics

The paramedics were unknown to me at the beginning of the project and whilst they were very friendly, lack of contact with them on the ward meant that it was hard to get to know them well. However, because they appeared more accepting of lay participation in care and because they appeared to want to develop their multidisciplinary relationships, I believe they approved of what I was trying to do. Before the project was introduced some of the paramedics had not been invited to multidisciplinary team meetings on the ward and I think they felt their subsequent attendance at such meetings was a positive outcome of the research. However, as time went on I think those who had been with the project the longest perhaps became a little disappointed by the lack of change achieved and frustrated by the apparent resistance to the project:

P *"I think maybe we ..... it feels that we haven't got that far. It feels as if a lot of time has been spent on the medical aspects, on things like medical cards and getting house officers into line, and sorting all that out, the very basic lay participation in care things, that we haven't advanced any higher."*

R *"How do you feel about that?"*

P *"A bit disappointed - it all sounded so wonderful at the beginning. It feels like there has been some resistance as well."*

R *"Let's think about that resistance. Where has it been coming from and why?"*

P *"Well, I think I have noticed resistance from the nursing staff on the ward round and maybe the house officers with the medical things."*

R *"In what way?"*

P "Well just resistance to carrying out tasks"

R "Why do you think that resistance ..... "

P "It's change, isn't it. There is always resistance to change"
(Paramedic: P8(E)p3)

This resistance caused some paramedics to withdraw from the ward as it became less worthwhile for them to be involved in the project. Some expressed feelings of guilt at withdrawing and sensed they were letting me down. However, as discussed later, the effect of withdrawal on the group dynamics did not make change any easier. It sometimes was hard to do what was in the best interests of an individual when it would have effect on the other participants. This highlights the need to establish acceptable ways of withdrawing from a project. Participants should feel "safe" to express their views freely and to withdraw at any time without feelings of guilt. Alternatively if their withdrawal is likely to have a detrimental effect on the group dynamics, participants should be encouraged to engage with the project ideas for a specified period of time, after which their involvement should be renegotiated.

Relationship with the new charge nurse

I believe my relationship with the new charge nurse was open and honest and perhaps therefore less threatened. In comparison with the original charge nurse, she was able to use me more effectively as a facilitator of change. She did not appear to be threatened by me or by the need to change practice on the ward. She described herself as being "in a rut" and welcomed the opportunity to have someone to help her reflect on and develop her practice:

"I had been a sister on the surgical ward for eight years and knew I needed to change, feeling in a rut. I had just completed a part time degree so the time seemed right for a move. Going to the medical ward was a sideways step but I felt that it would be challenging mainly because of the research that was being carried out there. I was excited about the research for two reasons. Firstly because I really wanted to work with Julienne. I knew that she would help facilitate my ideas into practice and also that she would be supportive to me personally, in the kind of ways that I had always felt I needed but had never received in the past. I found the idea of introducing change and innovation into practice very challenging. I didn't feel threatened by this because I felt going to

this ward I would have the skills, confidence and support to run a ward that I wished I'd had when starting eight years previously.

During the time that she remained on the ward I think Julienne and I worked really well together. She was an invaluable resource for me in terms of ideas and was extremely supportive. This support continued for a long time after the research period ended and I valued it enormously. I learnt a lot about how to affect change, the main points being that it can't be done quickly and that it takes an enormous amount of effort and personal investment. Despite the many difficulties, I look back on my time on the medical ward as the most fulfilling time of my clinical career."
(personal communication 1995)

Clearly the charge nurse has a key role in change (Pembrey, 1980). This highlights the importance of negotiating access to a site in which the leader is sufficiently dynamic to lead the change and also one who is capable of accepting constructive criticism from colleagues without feeling unduly threatened.

Thus it can perhaps be construed that whilst many participants respected me as a person and felt committed to the project verbally, my relationships with them were hampered by such issues as transience and a lack of power to influence change. Having explored the relationships between myself and the main participants the following section addresses some of the issues arising during the process of the research. One of the first issues to emerge was the need to review constantly my relationships with participants recruited to the study.

THE NEED FOR CONSTANT REVIEW OF RELATIONSHIPS

It became clear that in an action research project the relationships between participants and the action researcher need to be constantly reviewed. As discussed earlier I encountered considerable difficulty adjusting to the role of working as an action researcher on the ward. It was difficult for both participants and myself to sort out the role I should play on the ward. Orally I informed participants that I saw myself as a facilitator rather than as a leader of change. I explained that I did not want to try and force participants to co-operate with the research ideas because, unless they owned the research ideas, the changes would only flounder once I had left the ward. I suggested that one of the ways to judge an action research study was by its continuation after the action researcher had left the field and so I wanted to facilitate and support them in their own ideas rather than impose upon them my values. Given that there was some confusion as

to who was leading the change and a belief that the original charge nurse felt that the project ideas were being imposed on the ward, it may have been prudent to have developed a mutually agreed code of practice with the participants so that such issues could be addressed as and when they arose during the study.

A mutually agreed code of practice would have enabled me, as a researcher, to feel more readily accepted and comfortable in my role. I found it very difficult to work in the circumstances described and much of what I record in my field notes concerning the process of doing research, is about my acceptance on the ward. A code of practice would have also helped to clarify my position with new members of the multidisciplinary team. However, it is impossible to predict events when dealing with a changing environment and therefore any code of practice should be developed and modified in collaboration with the participants. Thus a code of practice would help both researcher and participants address sensitive issues as they arose in a mutually acceptable manner.

The following section now explores in more detail some of the sensitive issues which arose during the course of the study. One of the most sensitive issues which arose concerned the ethical dilemma associated with ensuring anonymity and confidentiality. In an action research study the participants themselves may not respect values, such as, anonymity and confidentiality, and the small size of the study may make individuals feel more vulnerable to being identified with the product of the research.

ETHICAL DILEMMAS ASSOCIATED WITH ANONYMITY AND CONFIDENTIALITY

With great difficulty I have endeavoured to write this case study in a way that the participants will feel I have represented their perspective without revealing their identities and making them feel vulnerable. It is noteworthy that this issue forced one action researcher to place an embargo on her thesis being read for several years (Scott, 1988). However, the passage of time and the transient nature of the work force both created and, to some extent, resolved this problem. Because the present study took place over several years and participants were often transient members of the multidisciplinary team, it has not been possible to keep in touch with all those who were involved in the change process. This has made it impossible to check with participants that they are comfortable and in agreement with the final report. It has taken the passage of time (five years) and the realisation that nearly all participants have moved away from the ward for me to feel more at ease with writing publicly about the problems encountered in the course of doing this research. I have also come to realise that these issues are important and relevant to others working in health care settings and I very much trust that by attempting to write an

account that is free from bias, participants will not feel let down or made to feel vulnerable by my final report.

The issue of vulnerability is addressed by other authors (Berg and Smith, 1988; Lee, 1993; Renzetti and Lee, 1993) and it is supportive and therapeutic to read their accounts and to share discussions with colleagues from other disciplines, such as Medical Sociology and Education, who are similarly troubled by some of the ethical dilemmas that arise in the process of doing either collaborative research or research in sensitive areas. However, I remain concerned that it is not really possible to protect completely individuals from being identified and believe that this is another important issue to be explored with participants at the stage of negotiating access.

The present study attempted to give participants ownership of the data. Findings were discussed in weekly multidisciplinary team meetings and at more formal presentations and transcripts of all interviews were made available to individuals for alteration as desired. In situations where I felt participants were particularly vulnerable, I even discussed sharing the chapters of the thesis as it was written. More so than other types of research, action research provides the opportunity for participants to confirm or reject the findings and this is seen to add to the validity of this type of work. In this way participants are in a position to control what data are shared with the wider audience and thus protect their own identities. However, whilst the researcher can assure participants that no one is named in the thesis, the researcher cannot control what participants say to each other in the field and, as such, vulnerability of individuals may still remain an issue. Perhaps this kind of thing should be discussed when negotiating access.

Furthermore anonymity and confidentiality may also be compromised by the fact that the researcher can easily be associated with having worked on a particular ward during data collection and therefore many people within the organisation reading the finished thesis are likely to be able to identify key participants. This can make participants feel particularly vulnerable, especially when previously hidden issues are brought out into the open. As the original charge nurse said:

> *"It is like someone coming into your flat and rearranging the furniture ..... it's like washing you dirty clothes in public"*
> (Field Notes: R(F)p276)

Another problem relating to the issue of confidentiality in this kind of work concerns the extent to which participants understand what may be shared with a wider

audience in the name of research. Interestingly, whilst all participants were asked to vocalise any objections or concerns they might have about the data during the course of its collection, few exercised their right to do so. Participants were more concerned with the way in which they had expressed themselves rather than the actual content of what was said. Several corrected the grammar in the text of their discussions and were anxious to sound more articulate in the transcript reflected. Only one participant wished to alter the content of her interview, and only one expressed concern after her senior manager felt that the interview had not reflected their professional group in a good light. This lack of concern to alter the content may reflect an implicit trust in me or, alternatively, a naiveté and lack of understanding as to what might constitute a research finding. Ball (1984) found that in his ethnographic study of a comprehensive school, the teachers clearly had little idea of what was meant by sociological research and the sort of outcomes it might produce. It was only when he gave them chapters of his thesis for comment that some of the teachers objected strongly to the findings, because they felt they had been unfairly represented. Thus the responsibility of getting the account right and making it meaningful to those less familiar with the setting, as well as endeavouring not to place individuals in a vulnerable position has been quite arduous. However, with time I have been able to present my research findings at lectures, conferences (Meyer, 1991; Meyer, 1991a; Meyer, 1992; Meyer, 1992a; Meyer, 1992b) and in publications (Meyer, 1993; Meyer, 1993a; Meyer, 1993b) and have grown in confidence that they have been meaningful to others to date. Those outside the project have not identified the setting or the participants involved. However, it does raise the ethical issue of placing individuals in a vulnerable position without being more aware of the implications and the value of addressing such an issue when seeking ethical approval.

LIMITS OF INFORMED CONSENT IN ACTION RESEARCH

A third issue arising from the study concerns the extent to which participants can truly give informed consent when the nature of the proposed change is unknown and determined by an emerging reality. Seaman (1987) gives the following definition of informed consent:

> *"Informed consent means that the subjects have full knowledge and understanding about the research project in which they are being asked to participate."*
> (Seaman, 1987, p22)

In the present study, care was taken to select a multidisciplinary team that was interested not only in the ideas of lay participation in care, but also in having me as a member of their team to facilitate change. However, on reflection I believe participants

were hindered in their ability to make an informed decision to take part in the study by both their lack of understanding of what was meant by lay participation in care and also the nature of action research. Thus, I question whether it is ever possible, in this type of study, to obtain informed consent. Part of the process of action research is for participants to identify what changes they wish to make and so it is not possible to know in advance what issues are likely to be identified. Given that not all participants agree on what change is needed, there will probably always be some participants who feel pressurised to change in a way that is not fully acceptable to them.

I now realise it is not enough to offer the opportunity to withdraw if there are any problems with a project. When it became apparent to me that the original charge nurse was uncomfortable with my presence on the ward I subsequently offered to withdraw, but other participants felt betrayed and wanted the project to continue. They felt they had invested much time and energy and wanted the issues raised by the project to be addressed rather than being swept under the carpet. However, it is very difficult to be true and fair to all those involved. Whilst action research relies on willing and voluntary collaboration, this is difficult to achieve in reality when working with a group of people.

Future action research studies would do well to explore such issues with participants in advance of the innovation to establish ethically acceptable means of dealing with conflict as it arises in the field.

POTENTIALLY THREATENING NATURE OF A COLLABORATIVE RELATIONSHIP

Collaboration implies an equality of relationship between researcher and participant which theoretically is not present in other types of research. Empirical research is concerned with prediction and control and requires the researcher to keep a distance from subjects so as not to contaminate findings. They are owned and interpreted by the researcher and only shared as a finished product. Within the interpretative tradition of social science, concern is more with meaning and understanding; the researcher takes account of the actor's perspective but still maintains control, judging what is said against the researcher's own frame of reference. A collaborative approach assumes that research is done *with* and *for* people rather than *on* people (Carr and Kemmis, 1986). It attempts to redress the unequal balance of power in the researcher-participant relationship. However, I question to what extent this is really possible.

Action research requires participants to work together democratically. For those more used to authoritarian modes of work, this can be quite threatening. In particular the

original charge nurse found it difficult to accept a new mode of interacting with her staff. She interpreted suggestions for change as a comment on her practice and perceived it as a challenge to her authority. During meetings she appeared uncomfortable when staff expressed their opinions openly. My field notes record her reaction after a meeting during which the discussion had become quite heated:

> *"I was left in the room with charge nurse and she said 'Look at what you have done'. I asked if I had done this or was it there before. She quietly said that she supposed it had been there before. ..... I feel a sense of guilt. In the meeting, because people were speaking so openly I felt I wanted to collect data and so did not control the direction of the conversation. In retrospect I felt I was making charge nurse and the staff nurses confront painful issues ..... On the other hand, I had not asked them to talk about these matters, perhaps there had been a build up of feelings on the ward and this meeting was a place where people could let off steam."*
> (Field Notes: R(F)p462/463)

It was as though the issues being discussed had always existed but had never been addressed openly on the ward. By introducing a process where participants were invited to share their views and make suggestions for change, the balance of power shifted and the original charge nurse felt a loss of control. For example, at exit interview she said:

> *"The whole ward has been turned upside down and I just don't know who is in charge any more ..... It's been the worst year of my nine to ten years. ..... I haven't felt in control. ..... I don't blame you ..... the problems were there before but the research brought them out into the open ..... I said before it's like washing you dirty clothes in public"*
> (Nurse: N0(E)p16)

Thus the democratic processes inherent in action research gave rise to a talking culture that had not existed previously and the charge nurse found it challenging. From her perspective, she had not been able to anticipate the kind of changes that the rest of the multidisciplinary team wanted to make in order to introduce lay participation in care. Furthermore, the fact that I was present asking for suggestions and feeding back issues in an open and honest way had a profound effect on the group's dynamics. It made everyone re-examine their roles and responsibilities. It made me question whether I had the right to be the catalyst of such unwelcome unrest. It made me recognise the potentially threatening nature of a collaborative relationship between researcher and

participants. Working as a participant observer I was always ready to listen to people's stories in case they had something relevant to say on the subject of lay participation in care. However, this placed me in the invidious position of recipient of much personal experience. However neutral one tries to be in this situation, one cannot avoid the fact that this type of information is empowering and as such is threatening to others.

The researcher in action research also has other forms of power over the participants. The researcher is usually a temporary member in the field and as such knows that whatever change occurs, it will not have a permanent effect on them. Since the researcher is concerned with the process as well as the outcomes of the research, he or she, can feel safe in the knowledge that whatever happens, data will be gathered and the research report written, subject to the participants' approval. The participants are unlikely to refuse the researcher ownership of the data given that the researcher is likely to have ingratiated himself or herself as a close colleague and friend. Furthermore any differences of opinion as regards the data can themselves be viewed as research findings.

Another form of power that the researcher has over the participants concerns the fact that he or she is perceived by participants as an academic expert belonging to another world with which not all participants are familiar. As stated earlier I am not convinced that all participants fully understood the nature of social science and whilst they may have been theoretically willing for me to share the findings of the study with a wider audience, they may not have been able to envisage the precise nature of these findings in the completed thesis. In this way, despite the intention to offer an egalitarian relationship with participants, it is my belief that they are potentially in a vulnerable position which places them at risk of exploitation, betrayal and abandonment. Stacey (1988) makes this point when she questions whether there can ever be a feminist ethnography. She writes

> *"I find myself wondering whether the appearance of greater respect for and equality with research subjects in the ethnographic approach masks a deeper, more dangerous form of exploitation ..... precisely because ethnographic research depends on human relationship, engagement, and attachment, it places research subjects at grave risk of manipulation and betrayal by the ethnographer."*
> (Stacey, 1988, p.22-23)

Within my own research I became conscious that I was perhaps being manipulative in that participants warmed to me as an individual and agreed that I should use their data in my thesis. However, I was also conscious of the possibility that

participants were manipulating me. On reflection I believe some of the issues raised in the research were already known by the multidisciplinary team and the nurse managers. I felt that the research was used to address issues that had been ignored in the past. In this way I felt that I was being manipulated by the participants. Thus action research can be stressful not only to the participants but also the researcher.

RESEARCHER SELF-DOUBTS: WORKING IN ISOLATION

Whilst action research endeavours to work with participants to change practice, it seems ironic that many of the field notes reflecting on the process of doing the research describe a feeling of isolation. Because action research depends upon the interpersonal qualities of the researcher more than other traditional forms of research, I found myself working hard to be accepted by a multidisciplinary team. However, this need to be accepted by the team brought with it a feeling of isolation. Having to invest time and energy into creating positive relationships with participants in many ways probably over-emphasised the fact that, however hard one makes the effort, one can never achieve total acceptance within the team. In my role as action researcher I was known to be in the field for a limited amount of time to gather data and return to the academic world to write my doctoral thesis. Therefore, however hard I tried to be an "insider" and engage positively with participants, I was nonetheless known to be an "outsider". This gave a sense of isolation and engendered self-doubt. Ball (1993) acknowledges the self-doubts engendered by participant observation in natural settings and argues the need for self-awareness and reflexivity.

I also felt isolated in my commitment to the research. Whilst throughout the study I endeavoured to assist the participants in changing their practice in whatever way they deemed appropriate, I found that I was really the only one who was able to be truly committed to the research. Participants proved to be committed verbally to the ideas but in reality little change was achieved and this led to a sense of isolation and frustration within me. Whilst the research was my focus and raison d'être, for the participants it was often their lowest priority. I found participants depended on my encouragement and motivation but it became difficult to maintain the momentum whilst my efforts were not fully supported by key staff on the ward. At times I felt disappointed that we had achieved so little and felt I had been wasting not only my own, but also every one else's time. It was disconcerting not to be more in control of the situation and at times I felt angry that more effort was not being made to help the project work. Sometimes it was difficult not to take personally the lack of co-operation and I found myself having self-doubts about my ability to conduct an action research study. Being embroiled in the research, it was sometimes difficult to detach oneself and realise the variety of reasons

which prevented participants from becoming more involved in the research process. Thus at times I felt very isolated as an action researcher.

Another sense of isolation centred around the lack of role identity. I found both being a researcher and a facilitator very demanding, which was further complicated by being a nurse. Patients and staff did not always know how to relate to me and sometimes I found myself acting unexpectedly in the role of nurse Whilst I could rationalise this as being a way of integrating into the team, it also made me doubt that I was actually in control of the situation. This was very unnerving and again fostered feelings of self-doubt.

Throughout the project I also felt very conscious of not being able to give sufficient time to either my role as facilitator or researcher. There was always a tension in me as to whether or not I was fulfilling adequately both roles. On reflection, had the project ideas been better supported by the participants and had a more dynamic ward based leader been involved in leading the change, the feelings of inadequacy in me might not have been so great. This was an issue frequently referred to in my field notes and which left me experiencing feelings of self-doubt as a researcher and facilitator of change.

Change is difficult to measure. Thus another issue that I had to deal with was coping with the apparent lack of progress. Participants expressed feelings of disappointment in that more had not been achieved during the time and there were times when I found myself feeling similarly frustrated and disillusioned. One such occasion was when, having waited two months for an answer from the hospital solicitor as to the legal implications of lay participation in care, it became apparent that the senior nursing staff had not actually written to the solicitor as promised. The multidisciplinary team had felt unable to proceed with the project ideas without first clarifying their legal position and it was infuriating to feel that so much precious time had been wasted because it had not been the priority of another person on whom I had depended. The field notes record how this frustration led to feelings of apathy:

> *"The worst day of the project so far! I feel worn down and exhausted. I know I should write my field notes immediately to express my anger but I am starting to feel apathetic myself. Perhaps I am going native!"*
> (Field Notes: R F)p212/213)

Again I was left with feelings of inadequacy, isolation and vulnerability. However, by taking on a research approach in which the realities of practice are confronted, it is perhaps understandable that such feelings should emerge. It possibly highlights the need for emotional support for researchers when carrying out this kind of research. Whilst the issue has been recognised by (Webb, 1989), it has yet to be recognised as a legitimate need (Johnson and Plant, 1995).

SPECIAL DEMANDS OF ACTION RESEARCH ON RESEARCHER

A further concern arising from action research is the special demands it places on the researcher and there appear to be several key reasons why this is so.

First, this kind of research cannot be pre-planned fully and therefore lacks some structure. The action researcher goes into the field with a flexible approach to adapt to the needs and concerns of the participants. Whilst this is a laudable endeavour, I argue that it places the researcher under enormous strain. It is difficult to carry out "on the spot" research because often there is little time to think creatively and work with problems as they arise. During the study I felt constantly under pressure to get on with the innovation, which left one with limited time only to reflect and consider in more depth the research methodologies being used.

Second, by working so closely with participants it was a constant concern to be free from bias whilst focusing on issues raised. For instance, over time I have become more appreciative of how difficult it must have been for the original charge nurse to examine her practice and confront the issues being raised by the multidisciplinary team. However, because at the time she was blocking all attempts to change practice, it was difficult to empathise with her. On reflection, I have come to realise that ownership of some of the problems encountered have to be owned not only by myself but also by the participants.

Third, in action research there is a need to feedback to the participants findings as they emerge in order to plan change. However, it was hard to make sense of the findings in anything more than a descriptive way because there was insufficient time to analyse them in more depth. I was only able to conduct a thorough systematic analysis of the data once I had withdrawn from the ward. Findings discussed on the ward at the time of the project tended to be what participants told me rather than a systematic interpretation of the data. Whilst I would have welcomed the participants' involvement in the interpretation of the data, by the time the data was more rigorously analysed many of the

participants had left. Thus action research is time dependent, which increases the demands on the researcher.

Fourth, this kind of research is extremely demanding because it is so difficult to combine the researcher and facilitator roles. At times during the study I found myself experiencing feelings of exhaustion and apathy. It was hard sometimes to motivate myself and to keep the project moving, as my field notes reflect:

> *"I question the quality of my research at the moment. I feel I am becoming a victim to the general apathy on the ward. I can feel myself being sucked in by it and I feel the need to stand back."*
> (Field Notes: R(F)p246)

Because of the commitment to facilitating ongoing change, it was not possible to withdraw from the ward in order to "recharge my batteries". There were meetings to administer and data to collect. On the few occasions I took a holiday, I would return to the ward to find the project had not advanced during my absence and participants were waiting for me to motivate and redirect them. After one Christmas I wrote:

> *"Returned to the ward following annual leave. Felt somewhat despondent. Whilst everyone was warm in welcoming me back - little appears to have been done in my absence ..... One student nurse commented as I tidied the resource cupboard 'You can tell you are back because the place is starting to become organised again'."*
> (Field Notes: R(F)p166/167)

Finally there was the issue of withdrawing from the ward. Unlike other kinds of research which are not dependent on change, it is difficult to know when to withdraw from an action research study. Having been in touch with the ward for eighteen months and having collected data for a year, I had sufficient data for my doctoral thesis. However, it was only after this time that change started to take place in a meaningful way. The appointment of the new charge nurse heralded new developments on the ward and I felt a moral obligation to continue my contact with the ward. I felt responsible for having initiated the project ideas and felt obliged to help participants until they felt they no longer needed me. This placed particular demands on me as a researcher as it extended the period of data collection, thus delaying the analysis and writing up process. This was further compounded by the fact that action research uses a variety of data

collection methods to triangulate findings, which means that the research process in this instance has been extremely protracted and time consuming.

Ball (1993) highlights the stresses and tensions of the fieldwork process. He suggests that fieldwork "involves a personal confrontation with the unknown and requires the aspirant to come to grips with the use of theory and method in the context of a confused, murky, contradictory, and emergent reality" (Ball, 1993, p44). I would argue that action research, with its focus on changing practice, places additional pressures on the researcher and would advocate the need for researcher support in this type of work.

SUMMARY

This section of the thesis has explored my reflections on the process of carrying out action research. It explores my relationships with participants and highlights the need for the constant review of relationships in action research. It addresses some of the ethical issues concerned with anonymity, confidentiality and informed consent in relation to action research and makes suggestions for consideration in future studies. It describes some of the special demands placed on an action researcher and highlights the need for support in this role.

These reflections demonstrate that by working closely with participants I was able to obtain rich and complex data. Furthermore by working with the realities of everyday practice I believe the findings will be more meaningful to practitioners. Thus it has been possible to move beyond the rhetoric of lay participation in care and present a more honest portrayal of health professionals' attitudes towards this concept. By using a flexible approach to gather data, it has been possible to take advantage of the unique situation which arose when health professionals were asked to examine their practice and work collaboratively. By concentrating on the research process as well as the research product it has been possible not only to add to the body of knowledge on lay participation in care but also to add to the body of knowledge on changing health care practice. I hope also that by writing this section of the thesis and exploring the relationships I had with the participants, and some of the issues that arose in the process of doing the research, that I have given a reflexive and honest account which the participants would want to own and endorse. In so doing I hope to have produced a study which has not only taken account of the power imbalance in research but also attempted to be less exploitative of the participants.

ISSUES FOR FUTURE CONSIDERATION

INTRODUCTION

Whilst one cannot generalise from case study data, nonetheless some important issues are raised by the study which are worthy of future consideration. The issues raised are related, not only to future practice, but also, to future research.

FUTURE PRACTICE

1. Health professionals need to be better prepared (knowledge, attitudes and skills) for the more educative and supportive roles, which are being advocated in current policies, in the name of "consumerism" and "health promotion". Health professionals need to be able to share knowledge with lay people through empowerment. This has implications for both pre-registration and post-registration education and is relevant to all the professional disciplines.

2. Health professionals need to learn to participate more with each other by holding common philosophical understandings and approaches to patient care. This has implications for common core curricula and joint interprofessional teaching. It also has implications for greater interprofessional collaboration in all spheres of health care (practice, education, management and research).

3. If government policies are to persist in emphasising individual responsibility for health, there is a need to re-educate the public with respect to their expected future roles in health care. Policies should indicate more clearly their philosophical and political underpinnings.

4. Health professionals, working in both hospital and community settings, need to liaise more closely with each other and with patients or clients and their close family and friends, to foster more realistic expectations of health care, as dictated by economic constraints.

5. There is a need for a range of cultures in health care practice. In particular, creative and flexible cultures need to be nurtured to cope with change and adaptation. Areas of innovative practice need to be supported physically with adequate resources and psychologically to cope with the emotional demands of changing practice.

6. Careful consideration needs to be given to the future selection of managers (all disciplines) to ensure they have the qualities of dynamic leadership to initiate and direct change. Furthermore, if change is to be properly managed, there is an urgent need for professional development of those managers who are not perceived to be dynamic leaders.

7. Roles within the health care team need to be made more explicit within a supportive culture which fosters greater understanding of the varying roles and responsibilities of different health professionals. In particular, more democratic approaches to interprofessional relations are needed.

8. Patterns of work need to be addressed to support change in practice. In particular, the issue of transience in teaching hospitals and the development of practices to foster individualised care need to be considered.

FUTURE RESEARCH

1. The study highlights the limitations of using structured instruments to measure complex phenomena, such as attitudes towards lay participation in care. Future research should examine such phenomena in the reality of practice, using more qualitative methods (participant observation and in-depth interviews).

2. There is a need for further exploratory research on health professionals' attitudes towards lay participation in care. In particular there is a need to establish whether the views held by the participants in this study are unique or held more generally in the professions. Such research should focus on the health professionals' understanding of the philosophical and political underpinnings of lay participation in care and also address their concerns about its use in practice.

3. Future research should address the public response to lay participation in care, in particular focusing on the views of patients or clients and their close family and friends both in hospital and community settings.

4. The study also highlights the need for exploratory research to examine the different ways lay participation in care might be developed in practice. Such a study should closely monitor the process and outcome of introducing such changes in practice.

5. There is a need for further exploratory research on interprofessional relationships. In particular, there is a requirement to identify examples of good interprofessional collaboration which can be used in future practice.

6. Future research should also focus on professional-client relationships in the reality of practice. Evidence should be gathered on the patient or client's perception of any changes in relationship.

7. Research is needed to assess the impact of recent policy initiatives on health professionals in terms of their morale and ability to address new ideas.

8. A variety of research approaches in health care practice should be encouraged. In particular, new paradigm methods should be supported, due to the imbalance in funding, compared to more traditional methods.

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APPENDIX I

DIARY OF EVENTS

February	1988	Negotiation of access within hospital.
June	1988	Selection of ward. Ethical clearance. Feedback letter to non selected hospital wards.
July/August	1988	Orientation to ward as insider researcher - role development. Commencement of daily field notes monitoring research process. Consultancy work within hospital. Development of research methods - pilot work. Commencement of ward profile (staff and patients).
September	1988	Commencement of main data collection. - Pre-innovation ward assessment (QUALPACS, observation of LPC). - Ward assessment over time (nursing process, ward learning environment). - Initial interviews on lay participation in care - multidisciplinary team (MDT). - Continuation of pilot work (patient, relative and friend - interviews and questionnaires).
October	1988	Continuation of main data collection. Negotiation of channels of communication.
November	1988	Feedback of findings to multidisciplinary team. Establishment of weekly multidisciplinary team meetings to discuss and review progress project ideas. Establishment of twice weekly feedback and planning meetings for nurses. Development of Lay Participation in Care Policy. Development of Key Nurse System. Establishment of contact with Health Promotion Unit. Introduction of new nursing documentation on ward - teaching sessions. Introduction of MDT communication sheet.

November	1988	Application to League of Friends for money to develop patient teaching resources. Establishment of weekly feedback sheets on MDT meetings
December	1988	Development of key nurse system. Letters to professional bodies concerning professional liability. Development of system for patient drug education (medicine reminder card). Endeavours to improve multidisciplinary team communication. Development patient teaching resources on the ward.
January	1989	Commencement of medicine reminder card (MRC) trial. Discussions with community nurses about project ideas. Confrontation of apathy - reaffirmation interest in project ideas. Establishment of weekly ward organisation meetings (to be run by nurse in charge of shift, not researcher) Commencement of consultant vetting patient teaching resources.
February	1989	Development of mentor system for learners. Allocation of maintenance of geographical area to qualified staff. Development of teaching programme and support group for learners. Development of care planning rounds. Letter from professional bodies supporting project ideas. Lack of support for project from charge nurse (offer to withdraw). Project ideas supported by other MDT members (encouragement to continue by nursing hierarchy). Interviews with district senior nurse managers. - information giving - gaining professional perspective on LPC in community. 6 month review of project with ADNS, CNM and charge nurse. Development of policy statement on LPC.

March	1989	Attendance of CNM at meetings to offer more support to the ward. Development of patient information letter on LPC. 6 month review of project with consultants. Development of patient education resources - directories of local support groups. MDT case conference with patient and wife arranged to discuss LPC. Commencement of patients' experience of special investigations record. Commencement of patient centred discussions on LPC.
April	1989	Orientation handout for new staff. Resignation of charge nurse. Advertisement of charge nurse's post to continue project. Creation of new post - ADNS (Special Projects) to monitor initiative Appointment of internal applicant as new ward charge nurse. Interviews with district SNMs.
May	1989	Commencement of exit interviews. Cancellation of meetings - state of flux with change of charge nurses. Renegotiation of project in view of new charge nurse being appointed. Appointment of acting charge nurse. Introduction of team key nurse system. Commencement of post-innovation ward assessment.
June	1989	Orientation of new C/N to project. Negotiation of roles with new C/N - interested in getting more involved with research process as well as innovation (to register for own PhD and seek money to continue innovation). Discussion with nursing hierarchy about possibility of establishing a nursing research development unit to continue to monitor project (apply to King's Fund, formal links with University). Application to League of Friends for more money to develop patient teaching resources.

July	1989	Commencement of new C/N in charge of ward. Process of handing over project to new C/N and researcher beginning to withdraw from the ward. Continuation of MDT meetings - new C/N in charge. Renegotiation of researcher support for project.
August	1989	Commencement of general support meetings for new C/N. Informal appraisal of staff by new C/N. Re-establishment of team key nurse system. Restructure of patients day. Redistribution of roles and responsibilities in ward management. Staff support and development by charge nurse. Development of mentor system for learners. Development of ward objectives for learners.
September	1989	Introduction of "incident" book. Commencement of bedside handover. Decentralisation of nursing. Re-establishment of patients' experience of special investigations record. Development of ward co-ordinator's advisory, educative and supportive role. Inquiries into developing "quiet room" for patient teaching and counselling. Discussion with ADNS (Special Projects) about future monitoring of project. Dependency and skill mix investigation.
October	1989	Creation and appointment of junior charge nurse. Discussion with management concerning lack of support for project. Closure of beds. Application for local research grant to continue monitoring innovation.
November	1989	Period of consolidation and monitoring of project by charge nurse.
December	1989	Period of consolidation and monitoring of project by charge nurse.
January	1990	Period of consolidation and monitoring of project by charge nurse.

February	1990	Period of consolidation and monitoring of project by charge nurse.
March	1990	Application to DoH for research studentship to investigate lay perceptions of LPC.
April	1990	Awarded local research grant to continue monitoring project.
May	1990	Staff interviews reviewing progress of project.
June	1990	Report submitted to region highlighting issues from project. Charge nurse awarded DoH research studentship.

APPENDIX II

FEEDBACK AND PLANNING MEETINGS

Date	People	Content
25/7/88	Consultants (1 and 2)	Feedback ethical approval. Update on progress of ideas. Future communication channels.
3/8/88	CNM	Feedback ethical approval. Update on progress of ideas. Future communication channels.
11/8/88	ADNS (1)	Feedback ethical approval. Update on progress of ideas. Future communication channels.
20/9/88	ADNS (1)	Update on progress of ideas.
7/10/88	ADNS (2)	Establish contact with new ADNS - ADNS (1) having left. Update on progress of ideas. Future communication channels.
8/11/88	Charge nurse	Feedback of issues from interviews. Review suggested changes. Renegotiate project continuing.
10/11/88	Charge nurse and Staff nurses	Feedback issues from interviews. Review of suggested changes. Plan introduction of key nurse system. Establish twice weekly feedback meetings for nurses.
15/11/88	Consultants (1 and 2)	Feedback of issues from interviews. Review suggested changes. Establish weekly multidisciplinary team (MDT) meetings to discuss and review project ideas.
15/11/88	DNS	Update on progress of research. Establish meeting with DNS, ADNS and charge nurse to discuss policy on lay participation in care.
15/11/88	Qualified nurses	Feedback issues from interviews. Review of suggested changes. Plan introduction of key nurse system. Agreed to write handouts on key nurse system and lay participation in care.

21/11/88	MDT	Feedback issues from interviews. Review suggested changes. Draft handout on policy for lay participation in care. Agreed to investigate professional liability and LPC. Agreed to seek money for patient education materials. Concern expressed over patients receiving mixed messages - all health education literature to be vetted by consultant. Agreed to write weekly feedback sheets on meetings.
22/11/88	Qualified nurses	Update from MDT meeting 21/11/88. Feedback issues from interviews.. Review suggested changes. Draft handout on policy for lay participation in care and key nurse system. Agreed to introduce new documentation (nursing kardex).
24/11/88	Qualified nurses	Update from MDT meeting 21/11/88. Feedback issues from interviews. Review suggested changes. Discussion on key nurse system.
28/11/88	MDT	Discussion on draft policy on lay participation in care. - rejected idea of patient access to medical records. - rejected idea of medics being available at set times to answer lay queries. - professional liability to be explored with hospital solicitor. - agreed to introduce MDT communication sheet.
29/11/88	Qualified nurses	Update from MDT meeting 28/11/88. Discussion on new documentation (nursing kardex).
1/12/88	Qualified nurses	Update from MDT meeting 28/11/88. Teaching session on new documentation.

2/12/88	DNS ADNS Charge nurse	Feedback of issues from interviews. Review suggested changes DNS to write to professional bodies re. professional liability. Agreed to inform DNS for Primary Care Services of project.
5/12/88	MDT	Delay in decision on professional liability. Need for expert to assess patient skills e.g. blood sugar monitoring. Hesitation to allow patients to monitor own observations and do surgical dressings. Discussion on need for patient education in hospital (drugs and diet).
6/12/88	Qualified nurses	Update from MDT meeting 5/12/88. Discussion on key nurse system - changes in roles and responsibilities. Agreed to obtain white board to display which patients were being looked after by which nurse.
8/12/88	Qualified nurses	Meeting cancelled (same nurses on ward as 8/12/88).
12/12/88	MDT	Discussion and development of medicine reminder card (MRC) system - trial period of 3 months (house officer to help design evaluation form for use in OPD).
13/12/88	Qualified nurses	Meeting cancelled (researcher not available)
15/12/88	Qualified nurses	Update on MDT meeting 12/12/88. Discussion on patient education. Discussion on key nurse system.
19/12/88	MDT	Discussion on MDT communication. - use of communication sheet. - relating to key nurses. Distribution of handout on key nurse system.
20/12/88	Qualified nurses	Update on MDT meeting 19/12/88. Review of key nurse system.
22/12/88 till 8/1/88	MDT Qualified nurses	Meetings cancelled - Christmas.

9/1/89	MDT	Review of medicine reminder card (MRC) system.
10/1/89	Qualified nurses	Update on MDT meeting 9/1/89. Review of problems with key nurse system. - nursing team not pulling together. - documentation not being completed. - old system being run at same time as new system. - internal rotation leading to discontinuity. - lack of leadership and monitoring.
12/1/89	Qualified nurses	Update on MDT meeting 9/1/89. Review of problems with key nurse system. Confronted apathy and renegotiated interest in project.
16/1/89	MDT	Review of MDT communication. Review of MRC system. Rejected idea of encouraging lay presence on ward rounds.
17/1/89	Qualified nurses	Update on MDT meeting 16/1/89. Report on ad hoc staff nurse meeting which discussed lack of progress with project (15/1/89). - reaffirmation that staff nurses wanted project to continue. - decision to run weekly ward organisation meetings. - change place of report from central station (avoid interruptions, improve quality). - organise mentor system for learners to ensure they are aware of changes.
19/1/89	Qualified nurses	Ward organisation meeting (run by staff nurse). - reviewed key nurse system problems. - care plan rounds to occur at beginning of shift. - teaching programme to be established. - qualified staff to oversee written documentation. - qualified nurses to be responsible for maintenance of geographical area. - identified need to discuss changes with charge nurse.

23/1/89	MDT	Review of MDT communication - felt to be improving with recent initiatives. Discussion on difficulties in maintaining change with transient workforce - orientation handouts to be designed. Still awaiting decision on professional liability.
24/1/89	Qualified nurses	Update on MDT meeting 24/1/89. Discussion with charge nurse about issues raised at ward organisation meeting 19/1/89. - accepted suggestions with pessimism.
26/1/89	Qualified nurses	Meeting abandoned - ward too busy.
30/1/89	MDT	Senior health education officer explained his role and offered support and help with project ideas (resources, teaching) Discussion on patient teaching materials - all resources to be vetted by consultant (prevent mixed messages).
31/1/89	Qualified nurses	Meeting cancelled (ward too busy).
2/2/89	Qualified nurses	Meeting cancelled by charge nurse (later expressed dissatisfaction with way project was developing). Agreed to discuss matter with nursing hierarchy.
6/2/89	MDT	Discussion on the vetting of health promotion literature. Discussion concerning lack of orientation for new house officers in relation to roles and responsibilities as regards project ideas.
7/2/89	Qualified nurses	Update on MDT meeting 6/2//89. Discussion concerning general lack of commitment to project ideas and possible withdrawal of researcher from ward. - staff nurses expressed wish for project to continue. - felt ward staff could not make changes on their own.

7/2/89	ADNS	Discussion concerning general lack of commitment to project ideas and possible withdrawal of researcher from ward. - ADNS expressed wish for project to continue. - other sources reflected charge nurse's reluctance to change (as a manager she would need to address this).
9/2/89	Qualified nurses	Meeting cancelled - future of project being discussed.
9/2/89	ADNS	DNS had expressed wish for project to continue. - acknowledgement that nursing hierarchy had not sufficiently supported project ideas. - project to be given more official recognition. - meeting to be arranged with charge nurse to discuss future co-operation.
13/2/89	MDT	Discussion concerning failure to implement MRC system. - new house officers not aware of roles and responsibilities. - MRC system not emphasised enough as a priority. Discussion on the vetting of health promotion literature. Letters received from professional bodies giving support to project ideas. Policy statement to be written by ADNS on LPC
14/2/89	Qualified nurses	Meeting cancelled (staff off sick).
16/2/89	Qualified nurses	Discussion concerning nursing hierarchy's support of project continuing. Discussion concerning need to improve teaching of learners - care plan rounds. - at report time.

17/2/89	ADNS and Charge nurse	Discussed charge nurse's reservations about the project. - felt criticised and threatened. - meetings too time consuming. ADNS specified need to be open to future change. Explored possible support needed to change. Charge nurse expressed dissatisfaction with changing role of ward charge nurse (too much emphasis on management and leadership). CNM to attend meetings and offer more support to charge nurse.
20/2/89	MDT	Proposed policy statement circulated for discussion. Review of MRC system - backlog in pharmacy. Agreed to design information letter on LPC for patients.
21/2/89	Qualified nurses	Update on MDT meeting 20/2/89. Discussed future commitment to project - need for honesty.
21/2/89	CNM	Updated with progress of research on the ward. Discussed charge nurse's need for more involvement and support from nursing hierarchy.
23/2/89	Qualified nurses	Discussed better support and teaching of students on the ward. Discussed lack of team cohesion in implementing new ideas.
27/2/89	MDT	Discussion on patient information letter on LPC. Vetting of health promotion literature continues. Agreed to write handout on MRC system for new house officers (to be put in orientation folder - for update by current house officers).
28/2/89	Qualified nurses	Update on MDT meeting 27/2/89. Discussion on patient's information letter on LPC. Discussion concerning need to develop team spirit.
2/3/89	Qualified nurses	Researcher not present at meeting (teaching).

6/3/89	Consultants (1 and 2) ADNS	6 month review of project progress. Discussion on issues related to medics. - conservatism stifling change. - lack of direction and monitoring of house officers. - medical dominance of MDT - lack of involvement with ward. - lack of time to address issues
6/3/89	MDT	Agreed patient information letter for use on ward. Patients to be given copy of discharge summary
7/3/89	Qualified nurses	Update on MDT meeting 6/3/89. Decision taken to circulate letters at weekend. Agreed to talk to students about proposed changes. Update on progress on MRC system. Meetings to encourage constructive criticism. LPC meetings to be focused around specific patients.
9/3/89	Qualified nurses	Researcher unable to attend meeting (teaching).
13/3/89	MDT	Review of MRC system - feedback from GP in community positive. - system still floundering (not part of routine practice). Patient education literature (CHD) now vetted - needs to be individualised (not overload patients). Orientation folder still not designed Letter circulated from DoH (SAC (N) (88) 28) concerning nursing routines and improving efficiency.
14/3/89	Qualified nurses	Update on MDT meeting 13/3/89. Patient centred discussion.
20/3/89	MDT	Patient education literature (alcohol and smoking) now vetted (not contentious). Patients may need to refer to local support groups. Leaflets being used by patients from other wards. Agreed to obtain leaflets on special procedures. Suggested started to document patients' experiences of special investigations to use in patient education. Article circulated on Co-operative Care Units.

21/3/89	Qualified nurses	Patient centred discussion. - realised that did not know patient in sufficient depth - needed to change way of thinking and approach to patients.
23/3/89	Qualified nurses	Discussion on complaints from school of nursing (ENB may close ward to learners) Ward aims and objectives being developed. Discussion concerning staff shortages. Decision to document meetings.
27/3/89 till 28/3/89	MDT Qualified nurses	No meeting - Easter.
29/3/89	Student nurses	Discussion about project and proposed changes.
3/4/89	MDT	MRC system reviewed. Copy of policy statement was circulated. Patient information letter reviewed. - not enough to just give it out (needs personal contact). Decision to now concentrate on patient data. - perceptions and attitudes to LPC as it is offered. Agreed to work with nurses as role model.
4/4/89	Qualified nurses	Meeting cancelled (too busy). Circulated orientation handout for new staff.
6/4/89 till 16/4/89	MDT Qualified nurses	Meetings cancelled (researcher on annual leave).
17/4/89	MDT	Meeting cancelled (insufficient time).
18/4/89	Qualified nurses	Charge nurse announced her resignation and now job. Discussion to introduce team nursing rather than work as individuals. - fear that some individuals would end up carrying others.

19/4/89	ADNS	Nursing hierarchy wish project to continue. - will make new charge nurse appointment with this in mind. - have written project into job description for new ADNS (special projects).
24/4/89	MDT	Discussion on future of project with charge nurse leaving. MRC system reviewed. Aim to complete vetting of literature in time for new charge nurse's appointment.
25/4/89	Qualified nurses	Meeting cancelled.- ward in state of disruption
2/5/89	New charge nurse	Negotiated roles - would like to be more involved in research process (? register for her own PhD). Shared concerns and doubts.
2/5/89	Qualified nurses	Meeting cancelled.- ward in state of disruption
4/5/89	Qualified nurses	Discussion on how project should proceed during changeover of charge nurses. Key nurse system seen to be failing. - lack of enthusiastic leadership. - old system and new system being worked together. - required a new way of thinking/approach to patients. - ward busy and understaffed.
8/5/89	MDT	Orientation handouts for new staff were circulated. Review of MRC system - seen as medical responsibility (want to continue to try and make system work).
9/5/89	Qualified nurses	Update on MDT meetings. System of team nursing now being implemented. - off duty written around this. Review of patient information letters. - not being distributed. Discussed nurses taking more of a role in drug education.

15/5/89	Consultant 1	Meeting to discuss new charge nurse's future role in the research project. Renegotiation of project continuing.
15/5/89	MDT	Meeting cancelled (insufficient people).
16/5/89	Qualified nurses	Meeting cancelled (nothing to feed back)
18/5/89	Senior Registrar and Registrar	Feedback of issues raised in research. - lack of management and direction for house officers. - task oriented nature of house officer's work. - lack of involvement with the ward. - seen as charge nurse's job to develop house officers. Decision to start new MRC when new charge nurse starts
22/5/89	MDT	Discussion concerning possibility of inservice education of staff for counselling alcoholics. Review of MRC system. Review of health promotion literature vetting.
23/5/89	Qualified nurses	Meeting cancelled - teaching session arranged instead.
23/5/89	CNM	Meeting to discuss changes on ward and issues arising. Renegotiate project continuing with new charge nurse.
29/5/89	MDT	Meeting cancelled - bank holiday.
1/6/89	Qualified nurses	Review of research to date with acting charge nurse. Planned to have key nurse system working by time new charge nurse starts.
5/6/89	MDT	Discussion concerning patient education. Agreed to contact League of Friends for money to buy more patient education material - audio tapes and player. Discussion about the need to develop folder on local support services available for AIDS patients. Suggestion that nurse attends MDT meeting to discuss AIDS patients in hospital (useful contacts for services).

6/6/89	Qualified nurses	Meeting cancelled - LPC lost direction without permanent charge nurse (concentrating on key nurse system only). Researcher input through attending ward reports and working with individual staff as requested.
12/6/89	MDT	Discussion on developing patient education resources. Discussion on introducing aromatherapy on ward.
13/6/89	New charge nurse	Spent day together orienting towards research project - discussed research and innovation to date. - discussed her role as a charge nurse/change agent. - discussed nature of multidisciplinary team. - understandings of lay participation in care. - review of patient teaching resources.
14/6/89	New charge nurse	Spent day identifying changes charge nurse would like to support on the ward. - continue to introduce team nursing and mentor system. - sees herself as educator/supporter of nurses. - role in monitoring care and innovation. - committed to multidisciplinary teamwork - identified need for formal support of project ideas. - her part as a role model. - professional development of individual staff.
15/6/89	New charge nurse	Spent day discussing further development of research. - reviewed research process to date and debated methodological issues. - explored gaps in the data - identified how data might be gathered in the future. - reviewed how her own PhD might develop from the project. - discussed funding sources to continue the evaluation.
19/6/89	MDT	Meeting cancelled - researcher teaching
20/6/89	Qualified nurses	Update on MDT meetings and new charge nurse orientation.

26/6/89	MDT	Discussion on patient education resources - vetting was never ending and should be left to new charge nurse to use her discretion. Discussion concerning the unsuitability of current patients for LPC. Review of MRC system.
27/6/89	Qualified nurses	Update on MDT meetings and new charge nurse orientation. Discussion on sense of waiting for new leadership. Review of key nurse system. - each patient now being given a named nurse. Discussed potential development of project with creation of ADNS (special projects).
3/7/89	MDT	Discussion concerning use of aromatherapy on ward. - scepticism shown towards its use as a treatment - to consult Division of Medicine. Review of MRC system - still not being given out by house officers - suggestion that nurses become more involved - house officers to go on drug rounds to familiarise themselves with drugs being used. Discussion on 3 monthly pattern of house officers on ward (unable to cope with MRC system till just about to leave).
5/7/89	Consultant 2	Review of issues raised through research. Asked to present findings to other medics in hospital.
7/7/89	MDT	Circulated articles on therapeutic massage for discussion concerning aromatherapy. Discussion on the increase in lay people questioning medical practice - recently had to change consent form.

17/7/89	MDT	Discussed the need to hand the project over to the new charge nurse who was to continue monitoring the developments in LPC. Researcher would start to withdraw from ward, time now being spent gathering post-innovation data and exit interviews. Agreed to offer once per week support for the project depending on needs identified by new charge nurse. Agreed that MDT meetings should continue but no one wanted to take over writing and distributing feedback sheets. Discussed open access to social services records and the implications for practice. New charge nurse discussed how she intended to approach her role as change agent.
1/8/89	New charge nurse.	General support meeting - discussed how busy ward had been. - discussed improved atmosphere on the ward - discussed changes in ward organisation - all staff had informal appraisal - senior staff had been identified as key nurses with junior staff appointed within their team. - restructured patients' day - qualified staff given defined roles and responsibilities in ward organisation. Discussed need for staff support and development. Identified a lack of support herself from own manager.
4/8/89	New charge nurse	General support meeting - qualified staff finding it hard to adjust to new responsibilities (lack of confidence). - identified need to work with each nurse to develop key nurse roles. - discussed improved communication on the ward (MDT relating directly to key nurses). - lack of LPC on ward rounds

8/8/89	New charge nurse	Met in charge nurse's free time to discuss future directions of project. - discussed individual staff needs for development. - discussed difficulties of moving away from task oriented practices. - discussed MDT communication (MRC now being given out) Reflected back on achievements and planned future developments - develop mentor roles - write objectives for students - decentralisation of nursing work - establish incident book to share ideas/difficulties Discussed the future data collection - identified need to gather lay perceptions of LPC
11/8/89	DNS ADNS	Review of issues emerging from project to date. Identified aspects of data still needed. Discussion on financial/research support to continue monitoring the project (to be discussed with new ADNS (special projects).
12/8/89 till 31/8/89		Researcher - annual leave.

1/9/89	New charge nurse	Met in charge nurse's free time to review the project. - discussed how individual staff were reacting to the changes on the ward. - discussed 'incident book' (staff communicate difficulties encountered). - move to bedside handover involving patients and key nurses. - key nurses giving out own drugs - nurses more involved in patient education. - patients starting to record their experiences of special procedures for use in patient education - discussed co-ordinator's role as being advisory, educative and supportive. - consulting hierarchy about building a quiet area on ward for patient education and support. - discussed lack of managerial support.
11/9/89	ADNS (special projects) New charge nurse	Review of issues arising from project to date. Identified future data collection needs and explored possible support from organisation (unable to commit support - about to go off on maternity leave). Endeavoured to pass responsibility for project over to hospital.
11/9/78	New charge nurse	General support meeting Discussed effect of project on charge nurse - exhausted. Discussed problems with staff taking on new roles (need for professional development to cope). Discussed effect on patient care during changeover of working practices (need for charge nurse to monitor standards). - discussed inter-staff conflict and issue of personal problems affecting work. Discussed feelings of isolation and lack of support from management.

18/9/89	New charge nurse	Meeting cancelled (ward too busy) - telephone support. Total lack of support for innovation. - support services inadequate. - patient and staff stressed and complaining. - inadequate staffing levels and inappropriate skill mix. - lack of support and action from management.
20/9/89	New charge nurse	Informal contact Discussed effect of struggling with changing practice in isolation with no practical support. - doubt what can be achieved (constantly having to chase everything up and getting nowhere, disillusioned)
22/9/89	ADNS Charge nurse	Meeting to discuss future direction of project Discussed lack of managerial commitment to project and need for more support if innovation was to be possible. Suggested looked at skill mix and dependency to argue case for more resources. Senior staff nurse to be appointed - may make a difference.
2/10/89	New charge nurse New senior staff nurse	Reviewed and summarised research to date. Discussed difficulties encountered moving staff away from task oriented practice to seeing patients more holistically. Staff learning to work collectively Key nurses not reporting back to co-ordinator. Tendency to call in specialists for patient education. Discussed MDT communication. Discussed new senior staff nurse's role as ward co-ordinator with new charge nurse concentrating on professional development. Discussed need for qualified nurses to develop skills of communication, supervision, teaching and organisation.

16/10/89	New charge nurse	General support meeting Discussed difficulties encountered on the ward (innovation not possible in current climate) - many patient deaths/stress. Dependency score 230 (normal 140) and skill mix inadequate 50% learners 1st warders, sickness and agency staff. Lack of managerial support - went to see DNS (beds closed). Charge nurse to apply for local research grant to continue monitoring innovation.
20/10/89	CNM	Review of issues from project - discussed lack of support
7/11/89	New charge nurse	General support meeting Approached by Deputy DNS to apply for regional money to continue monitoring project. Identified methods for evaluation. Discussed individual staff's coping with changing practice. Discussed effect of introducing a "talking culture" on the ward. Discussed improvements in MDT communication.
20/11/89	New charge nurse	General support meeting Some staff leaving - ?unable to cope with changes. New teaching programme established - staff contributing. Harassment of constantly chasing things up. Discussed how MDT meetings were medically dominated
December January	New charge nurse	No meetings arranged - ward climate not conducive to making further changes (time to consolidate)

8/2/89	New charge nurse	Discussed hospital crisis management due to cut backs and low morale - poor environment for change. Staff not leaving (?dependent on new charge nurse's support). Same problems occurring with MRC system Charge nurse to apply for DoH money to register for PhD to take research ideas on further. Agreed to have Qualpacs done to assess if any differences in quality of care.
5/3/89	New charge nurse	Discussed writing proposal for DoH research studentship. Discussed staff dependency on new charge nurse for support. Difficulties encountered by staff in co-ordinators role (hard to assess priorities). Good ward evaluations from learners. Ward meetings more constructive.
15/3/89	New charge nurse	Typed and sent off proposal to DoH.
8/4/89	New charge nurse	Attended research conference together. Discussed methodologies and action research approaches Awarded regional money to continue evaluation - marked appropriate time for researcher to withdraw and pass on ownership. Discussed issues relating to ward - medics confronted about their domination and able to explore medic-nurse relations. - identified need to stand back and allow staff to cope more on own. Awaiting DoH decision on research studentship.
June	1989	Report submitted to Region highlighting issues from action research study monitoring changes since new charge nurse's appointment. Charge nurse awarded DoH research studentship (full time) to investigate lay perceptions of participation in care.

APPENDIX III

WARD POLICY ON LAY PARTICIPATION IN CARE

Introduction

The increase in chronic illness within society dictates that many patients will be discharged home with ongoing illnesses. Research has shown that patients are unprepared for discharge (Roberts, 1975; Skeet, 1970) and the major burden of care lies with the family (Parker, 1985). Lay participation in care enables patients and their close friends or relatives to become more involved in their nursing care whilst in hospital in preparation for discharge home. This policy responds to the need for health professionals to take on a more educative and supportive role and complements the Philosophy of Nursing of X Health Authority.

Statements

1. A multidisciplinary approach to care will be facilitated by weekly meetings to discuss lay participation in care. All members of the multidisciplinary team will be welcome to attend including:-

    - Dietician
    - Doctors
    - Nurses
    - Occupational Therapist
    - Pharmacist
    - Physiotherapist
    - Social Worker
    - Speech Therapist

2. On admission all patients will be informed by letter that they and their close family and friends will be encouraged to participate in care, should they wish to do so. The key nurse will later discuss this with them (3-4 days after admission).

3. A system of open visiting to facilitate lay participation in care will be operated at the discretion of the nursing staff.

4. Lay participation in care will include:-

    Involvement in care planning and evaluation

Involvement in practical nursing

4.1 Involvement in care planning and evaluation

a. All patients will be assessed for their suitability to be involved in care. Assessment will be based on intellectual and physical capability and level of motivation on the part of the patient. Assessment will be made by the multidisciplinary team in conjunction with the patient.

b. The patient's close family and friends will not be approached to participate in care without the willing verbal consent of the patient.

c. Patients' close family and friends (where appropriate) will be involved in the daily assessment of problems, planning and evaluation of care.

d. The multidisciplinary team will be encouraged to use the multidisciplinary communication sheet in the nursing documentation to pass on patient information within the team.

e. Patients and their close family and friends will be informed of consultant ward rounds and encouraged to participate in the decision making process.

f. Formal channels of communication between patients (and their close family and friends) with the multidisciplinary team will be established and informal communication encouraged.

g. In special circumstances (e.g. complex discharge home) case conferences will be organised and attended by the appropriate multidisciplinary team members and patients will be invited to participate together with their close family and friends.

4.2 Involvement in Practical Nursing

a. Where able, patients will be encouraged to participate in all aspects of their practical care.

b. Depending on the patients' wishes and where able, patients' close family and friends will be encouraged to participate in all aspects of care.

c. Practical care will include such thing as:-

1. Meeting hygiene needs
2. Helping patients to eat and drink
3. Helping patients to mobilise
4. Monitoring e.g.
   - fluid balance
   - urinalysis
   - blood sugars
   - haemoccults
   - pulse
   - temperature
   - blood pressure
   - respiration
5. Treatments e.g.
   - surgical dressings
   - applying topical ointments
6. Rehabilitation

5. A system of key workers being allocated to individual patients will be used to facilitate continuity of care and ensure a qualified nurse's input in care planning.

6. Patients will be put in touch with voluntary and self help groups - see directories in the bookcase in office.

7. Opportunities for health promotion will be identified and facilitated - see health promotion leaflets. A link with the X Health Promotion Unit will be maintained.

8. Patient teaching will include information giving about their illnesses - see books in office. Patients undergoing stressful procedures will be asked to record their experience in a book so that the key nurse might better explain the procedure to other patients (research has shown this lessens anxiety and improves recovery rates).

9. Patients will monitor their own drug taking whilst in hospital (medicine reminder cards) thus allowing opportunity to ask questions about their regimes.

Evaluation

Regular feedback at multidisciplinary meetings (Monday) should ensure an ongoing formative evaluation.

References

Parker, G. (1985). With Due Care and Attention: A Review of Research on Informal Care. London: Family Policy Studies Centre.

Roberts, I. (1975). Discharged From Hospital . London: Royal College of Nursing.

Skeet, M. (1970). Home From Hospital . London: The Dan Mason Research Committee.

APPENDIX IV

WARD POLICY ON KEY NURSE SYSTEM

Key Nurse System - X Ward

Key Nurses

Name	Designated Area
C/N	Supervisor
S/N	
S/N	
S/N	
S/N	
S/N	
S/N	
S/N	
S/N	
S/N	
S/N	

NB. List of key nurse allocations (actual and covering) on white board at nurses' station - to be updated by nurse in charge on Sunday late shift.

If patient moves to a new area, responsibility for that patient is negotiated between Key Nurses but generally assumed to be geographical.

Key nurses wishing to change their geographical area (designated area) do so by negotiation with their colleagues and communication with the nurse in charge.

Introduction

In order to put lay participation in care into practice, it has been suggested that a modified form of Primary Nursing could be used on X Ward. Primary Nursing is a method of organising care that focuses on an individual qualified nurse being responsible for a patient throughout his or her hospital stay. A modified form of this might involve an individual qualified nurse being responsible for a designated area of the ward. These "Key Nurses" would be responsible not only for the planning and evaluation of care for the patients in their designated area but also for the teaching of student nurses working in that area and maintenance of the environment. The Key Nurses would constantly feedback their activities to the Charge Nurse who would act as overall supervisor ensuring the system was maintained and offering advice and support to the Key Nurses on the management of their patients. Key Nurses would also have to be prepared to cover for their colleagues (annual leave, sickness, nights off) in the role of floating nurse. By designating Key Nurses to specific areas it should be possible to know at any one time who is responsible for care being given to patients and has the potential of improving communication on the ward. This system of care allows qualified nurses to form a more meaningful relationship with individual patients and their close family and friends. It may also prove to be a system of professional development for staff nurses in preparation for their role as ward charge nurses.

Commitment - Key Nurses

Whenever on duty the Key Nurse will:-

1. Ensure case notes and nursing records have been read for her patients.

2. Introduce self to patients as their Key Nurse.

3. Ensure the patient and their close family and friends have been assessed for their involvement in care.

4. Identify with the patient a plan of care which offers him participation in care.

5. Be responsible for teaching and supporting the patient, family and friends with their individual needs.

6. Involve the patient, family and friends in the evaluation of care being given.

7. Ensure the plan of care is communicated to all members of the multidisciplinary team (especially charge nurse).

8. Liaise with members of the multidisciplinary team to ensure that the patient, family and friends gain maximum teaching and support whilst in hospital in preparation for discharge e.g.
   -inform pharmacist if patient commenced on new drug and requires education
   - contact the social worker and occupational therapist if likely discharge problems
   - refer patients to dietician, speech therapist and physiotherapist as necessary

Other Responsibilities

1. Feedback information to nurse in charge.

2. Be prepared to act as floating nurse for other colleagues when they go on night duty, annual leave and sickness.

3. Ensure own patients have been handed on to an identified covering nurse before leaving the ward for night duty, annual leave and sickness. Leave message for nurse in charge on Sunday late duty as to which key nurse is covering for your patients.

4. Check documentation has been recorded appropriately and educate student nurses where omissions have occurred.

5. Be responsible for the physical environment of own designated area e.g. arrange for light bulbs to be changed, curtains to be mended, cleaning to be done as required.

Supervision

1. Charge Nurse to act as overall supervisor
   - inform other health professionals know which nurse is responsible for which patient.
   - ensure key nurses are carrying out their duties
   - offer feedback to the key nurses on the performance of these duties
   - off duty written (where possible) to include student nurses working with their Mentor

2. Nurse in charge of shift should:
   - organise a care plan round ensuring each patient is seen by a qualified nurse each shift
   - communicate any changes to key nurses via documentation and verbal reports
   - goes through patients with each member of multidisciplinary team on arrival on ward to discuss changes
   - refers any queries to key nurses

APPENDIX V

HOSPITAL POLICY STATEMENT ON LAY PARTICIPATION IN CARE

X Health Authority
X Hospital
Policy on Lay Participation in Care

Lay participation in care is being introduced in X Hospital, initially on X Ward.

Introduction

The increase in chronic illness dictates that many patients will be discharged home with ongoing illnesses. Research has shown that patients are unprepared for discharge and that the major burden in care lies with the family. Lay participation in care enables patients and their close friends or relatives to become more involved in their hospital care in preparation for discharge home. Internationally, participation in health care is viewed as a basic human right and is supported by ideas on the nature of health and illness. This policy responds to the needs for health professionals to take on more of an educative and supportive role and complements the Philosophy of Nursing of the X Health Authority.

Policy

Patients and their close friends and/or relatives should be actively encouraged to participate in care whilst in hospital in preparation for discharge home. All persons should be assessed for their suitability to be involved in care based on their intellectual and physical capability and level of motivation. Assessment should be made by the multidisciplinary team in conjunction with the patient. Lay participation in care should include involvement in planning and evaluation as well as involvement in practical nursing. Practical nursing includes maintaining activities of daily living, monitoring and treatment of ill health and rehabilitation. The involvement of lay persons in care must be in accordance with the UKCC's Code of professional Conduct. The nurse would remain accountable for the care plan and involvement of the lay carers. The nurse should be responsible for educating and supporting the lay carers and for ensuring the pace of handover of care is safe for and acceptable to the lay care.

APPENDIX VI

MEDICINE REMINDER CARD

MEDICINE REMINDER CARD

NAME_____

DATE ISSUED_____

PLEASE TAKE THIS CARD WITH YOU WHEN YOU GO TO YOUR DOCTOR OR CHEMIST AND WHEN YOU COME BACK FOR YOUR NEXT HOSPITAL APPOINTMENT.

TICK OFF EACH DOSE AS YOU HAVE BEEN SHOWN. IF YOU FORGET, DON'T WORRY – JUST LEAVE THE SPACE BLANK.

REMEMBER

DO NOT TRANSFER YOUR MEDICINES INTO OTHER CONTAINERS.

TO THE PHARMACIST

PLEASE MARK EACH CONTAINER WITH THE CORRECT CODE LETTER.

WHEN ALTERNATIVE DRUG BRANDS ARE DISPENSED PLEASE AMEND THE DESCRIPTION COLUMN.

CODE	PRESCRIPTION/ DESCRIPTION	· USE · OTHER INSTRUCTIONS	TIME OF DAY	NUMBER	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
			BREAKFAST TIME																						
			LUNCH TIME																						
			DINNER TIME																						
			NIGHT																						
			BREAKFAST TIME																						
			LUNCH TIME																						
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			LUNCH TIME																						
			DINNER TIME																						
			NIGHT																						
			BREAKFAST TIME																						
			LUNCH TIME																						
			DINNER TIME																						
			NIGHT																						

APPENDIX VII

MEDICINE REMINDER CARD SYSTEM

Instructions for Medicine Reminder Cards

Introduction

Medicine Reminder Cards (MRCs) are being used on the ward to improve compliance with drug taking after discharge. The use of MRCs is being monitored at the Out Patient Appointment. Please can you ensure that MRCs are given out as follows:

1. House officers should issue MRCs to all patients as soon as possible after admission tot he ward. Time should be spent explaining what drugs are for and answering any queries. Patients should be encouraged to monitor their own drug taking (using the MRCs) whilst in hospital.

2. The nursing staff should be informed as to which patients have been given MRCs (list on drug trolley) so that they can reinforce their use on the drug rounds.

3. At discharge the pharmacist will send up a MRC with the TTAs. When ordering TTAs please ensure that the date of the next out-patients appointment is given (patients returning later than 4 weeks will require additional sheets).

4, On discharge, the house officers should give the MRC to the patient together with the TTAs and explain that the GP may prescribe a different form of the same drug in the community (trade and proper names should be given).

5. Patients should be told to bring their MRC to their out-patients appointment and be prepared to comment on its value to them.

6. The house officers should staple a MRC feedback to the inside cover of the patient's notes. A red sticker with "MRC" written on it should be put on the front of the notes to draw attention at the out-patient department.

7. Consultants and registrars working in the clinics should check the front of the notes to see if the patient has been given a MRC in hospital. The MRC feedback sheet should then be completed by them to assess its use to the patient (and/or relative and friend).

8. Patients should be given a further supply of MRCs to last them till their next out-patients appointment and a new MRC feedback sheet should be attached to the inside cover of the notes in preparation for the next out-patients appointment.

9. The completed MRC feedback sheet should be returned to Ms J Meyer c/o X Ward for analysis.

10. The pharmacist will ensure that sufficient MRCs and MRC feedback sheets are supplied to the clinics.

11. This trial will be reviewed each month at the Lay Participation in Care Meetings. Any comments or suggestions will be most welcome.

NB. MRCs and feedback sheets can be found in a folder in one of the wire baskets at the nurses' station. Completed forms should be returned in this folder.

MEDICINE REMINDER CARD FEEDBACK SHEET

HOSPITAL NUMBER..... .....

NO. OF WEEKS AFTER DISCHARGE.....

MRC AT OPD? YES NO

MRC USED AT HOME? YES NO

PATIENT AND RELATIVE OPINION

VERY USEFUL USEFUL NOT AT ALL USEFUL

COMMENTS

MEDIC'S OPINION

	EXCELLENT				POOR
COMPLIANCE?	5	4	3	2	1
KNOWLEDGE?	5	4	3	2	1

COMMENTS

APPENDIX VIII

PATIENT INFORMATION LETTER

X Hospital Address and Telephone

WELCOME TO X WARD!

Would you and your close family and friends like to be involved in care whilst in hospital? If so....please let the staff on X Ward know how we can help.

Some people may like to take this opportunity of being in hospital to learn more about their illness. Others may like to learn nursing skills which may be useful to them at home.

At the discretion of the patient, close family and friends will be welcome to be involved in the day to day nursing care whilst they visit. The staff on the ward will be happy to show you how this can be done and would like to offer you their support.

We want to make your stay on this ward a happy one and will do all that we can to make this so.

Below is a list of the staff who are looking after you:

Charge Nurse: _____

Key Nurse: _____

Consultant: _____

Senior Registrar: _____

Registrar: _____

House officer: _____

Other: _____

_____

APPENDIX IX

PARTICIPANTS' LENGTH OF STAY ON WARD IN RELATION TO MAIN STUDY

Table 34: Qualified Nurses - Length of Stay on Ward in Relation to Main Study

LoS	7/88	8/88	9/88	10/88	11/88	12/88	1/89	2/89	3/89	4 89	5/89	6/89	7/89
CNM													
312	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX
C/N													
100	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX		
119												XXXX	
120													XXXX
S/N													
101	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX
102	XXXX	XXXX	XXXX										
103	XXXX	XXXX											
104	XXXX	XXXX	XXXX										
105	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX		
106	XXXX	XXXX	XXXX										
107	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX					
108	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX					
109		XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX					
110	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX
111				XXXX	XXXX								
112				XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX
113				XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX			
114							XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX
115									XXXX	XXXX	XXXX	XXXX	XXXX
116												XXXX	XXXX
117													XXXX

CNM: Clinical Nurse Manager C/N: Charge Nurse S/N: Qualified Nurses
XXXX: Present on ward LoS: Length of stay on ward in relation to study

Table 35: Learner Nurses - Length of Stay on Ward in Relation to Main Study

LoS	7/88	8/88	9/88	10/88	11/88	12/88	1/89	2/89	3/89	4/89	5/89	6/89	7/89
3rd Yr													
n=2		XXXX	XXXX	XX									
n=1		XX	XXXX	XXXX	XX								
n=2			XX	XX									
n=1				X	XXXX	XXXX	XXX						
n=2					XXX	X							
n=1					X	XXXX	XXXX	XXXX					
n=1					XX	XX							
n=2						X							
n=1							XX	XXXX	XXXX				
n=1								XXX	XXXX	XXXX	XX		
n=1										XX	XXXX	XXX	
n=2											XXX	XXXX	XXX
n=3												XX	XXXX
n=1													X
n=2													XX
2nd Yr													
n=3	XXXX	XXXX											
n=1		X	XXXX	XXXX	X								
n=3							XX	XXXX	XXXX				
n=3									X	XXXX	XXXX	XXX	
n=2												XX	XXXX
1st Yr													
n=3	XXX	XXXX	XXX										
n=3			X	XXXX	XXXX	X							
n=3						XXXX	XXXX	XXXX					
n=3								X	XXXX	XXXX	X		
n=3											XXX	XXXX	XXX
n=3													XX

3rd Yr: 3rd year Learners 2nd Yr: 2nd year Learners 1st Yr: 1st year learners
XXXX: Present on ward LoS: Length of stay on ward in relation to study

Table 36: Medics- Length of Stay on Ward in Relation to Main Study

LoS	7/88	8/88	9/88	10/88	11/88	12/88	1/89	2/89	3/89	4/89	5/89	6/89	7/89
Cons													
302	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX
303	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX
S. Reg													
304	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX							
323							XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX
Reg													
305	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX							
327							XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX
HO													
306		XXXX	XXXX	XXXX									
307		XXXX	XXXX	XXXX									
317					XXXX	XXXX	XXXX						
318					XXXX	XXXX	XXXX						
325								XXXX	XXXX	XXXX			
326								XXXX	XXXX	XXXX			
330											XXXX	XXXX	XXXX
331											XXXX	XXXX	XXXX

Cons: Consultants S. Reg: Senior Registrars Reg: Registrar HO: House Officers
XXXX: Present on ward LoS: Length of stay on ward in relation to study

Table 37: Paramedics- Length of Stay on Ward in Relation to Main Study

LoS	7/88	8/88	9/88	10/88	11/88	12/88	1/89	2/89	3/89	4/89	5/89	6/89	7/89
Diet.													
413							XXXX	XXXX					
421									XXXX	XXXX	XXXX	XXXX	XXXX
O/T													
410	XXXX	XXXX	XXXX	XXXX									
419					XXXX	XXXX	XXXX	XXXX	XXXX	XXXX			
432											XXXX	XXXX	XXXX
Pharm													
411			XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX
Physio													
401		XXXX	XXXX	XXXX	XXXX								
420						XXXX	XXXX	XXXX					
429											XXXX	XXXX	XXXX
S/W													
408	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX	XXXX
S/T													
409*													
414*													
422*													

Diet: Dietician O/T: Occupational Therapist Pharm: Pharmacist Physio: Physiotherapist
S/W: Social Worker S/T: Speech Therapist
XXXX: Present on ward LoS: Length of stay on ward in relation to study
*: Not directly associated with ward - picked up occasional referrals

APPENDIX X

PHASE 1 - NEGOTIATION

Interview Schedule

I'd like to talk to you about a research project I'm interested in doing in this hospital, to see if you would like to get involved with it. I'll begin by telling you about myself and how the project originated. I used to be the charge nurse on Ward X and so I know the hospital quite well. That was about 5 years ago and since then I have been working as a teacher in another hospital. Whilst working as a teacher I completed an MSc in Nursing and following this have registered for a PhD as a full time student at King's College, part of the University of London.

As you can see I'm not employed as such by the hospital and so there is no need for anyone to feel under any pressure to co-operate with the research. However, having said that , I have been given an honorary contract by the nursing hierarchy to work as a research nurse and so they must be interested in my ideas.

The project has been funded by the University and is in the area of lay participation in care. For me lay participation in care is about non professionals getting involved in patient care in hospital. My concern is that patients are often discharged home inadequately prepared for discharge. I believe patients may benefit if they and their close family and friends were more involved in care from day one of being in hospital. Its about changing the health professionals' role from being an expert and always doing things for patients to a role more involved in educating and supporting the lay person to look after himself or herself. Perhaps I could illustrate with an anecdote. The mother of a friend of mine was admitted to hospital having had a stroke. She was going to be discharged home in the near future and my friend visited her one morning to find she was being taken to the bathroom by two nurses for a wash. My friend realised she was going to have to help wash her at home and asked the nurses if there was anything she could do to help. The nurses said, "That's very kind of you .....perhaps you could make those three beds over there"!! Clearly the nurses missed an ideal opportunity to educate and support a relative who was going to have to deal with many more nursing problems once the patient went home.

In our society the majority of illness is chronic and patients will be discharged home to cope with their illnesses. In the community the majority of care is done by lay people. My concern is what we are doing in hospital to help prepare them for this role.

Perhaps I should tell you a little bit about the original research proposal that was funded and why I did not like it. This may help you to understand my approach to research. The original proposal was about a researcher going on to 5 wards in a hospital and dividing these wards into two. On one side of the ward lay participation in care would be encouraged and on the other side of the ward the routine needs of the ward would be stressed. These two groups would then be compared using a battery of assessment tools e.g. well being scales. Personally, I think this project was doomed to failure because it was impractical. How could nurses be expected to carry out two systems of care on one ward? How could you control for variables and stop patients in one group talking to patients in the other? This could lead to some difficult situations with some patients wanting to know why they and their family and friends weren't being involved in care as much as other patients on the ward or why they were being encouraged to get involved when others weren't. Furthermore I thought it was unrealistic for a researcher to expect nurses to carry out care which had been planned by an outsider. Nurses didn't always carry out the care they had planned never mind the care planned by someone else. My approach to research is not like this. I want to use action research instead where the researcher and the practitioner collaborate together. By this I mean the researcher is an insider and works on the ward as a welcomed member of the multidisciplinary team. That's what I am trying to do at the moment; I am trying to identify 1-2 wards in the hospital that are a) interested in lay participation in care for their patients and b) want to have me as a member of their multidisciplinary team to facilitate this change in practice.

What I would offer to do is begin by identifying what is meant by lay participation in care and what the multidisciplinary team want to innovate. This study has to be multidisciplinary because it is meaningless just to do something with nurses alone when looking at patient care. I would also interview the patients and relatives; possibly after discharge; to see what (if anything) they would have benefited from getting more involved with on the ward. I would see my role as feeding this information back to the multidisciplinary team and for them to come up with some policy about what they would like to innovate on the ward. I would then act as a facilitator helping them put these ideas into practice. For instance, if the multidisciplinary team felt patients needed to be more responsible for their own drugs in hospital I would look into the feasibility of this and help to organise this change in practice. I would also go on the ward rounds and sit in on ward reports focusing the nurses, medics and paramedics' attention onto lay participation in care. I would never take responsibility for a group of patients but would see myself almost like a clinical teacher working together with nurses and teaching them about this type of care.

I would expect to stay for about 6 months gathering data as to the problems and issues which arise as a result of the innovation. I ma not concerned that this project succeeds or fails, all I want to do is describe what happens so that others may learn from our findings if relevant to them. After 6 months I would leave the ward and go on to another one in the hospital to do the same thing to see if the problems and issues encountered are the same. When I leave the ward I hope I would have set up systems so that the innovation continues in my absence. Action research stipulates this and it would be interesting to see whether the innovation has occurred just because there was a facilitator or whether any change had really taken place.

I want people to see the project as being very flexible and if after a while the multidisciplinary team feel I am no longer welcomed as one of their members then I would happily leave the ward. In action research it is very important that the researcher and the client work together and if this is not happening then it is time to move on. All that I would ask is that we record why I go. For instance it may be because of a personality clash or because the ideas of lay participation in care are not working. On the other hand it may be because staff are changing on the ward and its no longer thought appropriate for me to stay. I would not be upset if I was told to go.....to me this would be a finding in itself, so my time would not have been wasted. On the other hand if after 6 months the team felt they wanted me to stay as facilitator for longer because not enough had been achieved then I would document one case study rather than move to another ward and document two.

I'd like to explain what I am currently doing. I am interviewing all the charge nurses of adult medical and surgical patients throughout the hospital to identify wards interested in lay participation in care and interested in having me on their team to facilitate a change in practice. Following this I am interviewing the consultants of these wards to ascertain their views. I will then interview other multidisciplinary team members in order to identify one or two wards that would be suitable for the study.

Questions

1. How do you feel about the research ideas?

2. How do you feel about lay participation in care on your ward?

3. Can you identify any particular groups of patients that you think would benefit from this type of care?

4. How do you feel about me working as a facilitator on your multidisciplinary team?

5. Do you think other members of the team would accept the research ideas?

6. Would your ward to be considered for this project?

7. Is there anybody else you think I should speak to about the project?

Many thanks for your time in listening to these research ideas. I shall feedback to you by letter what happens in the future.

APPENDIX XI

RESEARCH PROPOSAL

TITLE OF PROJECT

Action Research: the systematic introduction of lay participation in care within the ward environment

PRINCIPAL INVESTIGATOR

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This research is being undertaken by means of a Junior Research Studentship awarded by the University of London

Summary

This study examines the effect of systematically introducing lay participation in care within the context of a ward environment using illuminative evaluation strategies. Much has been written about the increasing demand for lay participation in care. This need has arisen from changing patterns of illness in society and the movement towards self-determination. However, little research has been done in this field.

An action research approach will be used to innovate lay participation in care on 2 wards in a London teaching hospital. The researcher will work alongside health professionals acting as facilitator and evaluator for a period of approximately 6 months in each setting. In-depth case studies will describe the progress and impact of the innovation. Data will be gathered from patients, relatives, doctors, nurses and other health professionals using a mixture of qualitative and quantitative methods.

This research will be undertaken by means of a Junior Research Studentship awarded by the University of London. The principal investigator is registered with the Department of Nursing Studies, King's College (KQC) as a full-time student for PhD.

Title of Project

Action research: the systematic introduction of lay participation in care within the context of a ward environment.

Justification

The increase of chronic illness which society dictates that many patients will be discharged home with ongoing illnesses. Research has shown that patients are unprepared for discharge (Skeet 1970: Roberts 1975) and that the major burden of care in the community lies with the family (Parker 1985). It has been argued that involving patients and their relatives in care whilst in hospital might better prepare them for discharge. However, research has shown there to be limited lay participation in hospital care (Brooking 1986). Traditionally patients have been passive recipients of health care (Parsons 1951) and this research proposal is concerned with changing the role of health professionals to encourage more participation in care. Lay participation in care is seen as a major thread of health promotion (Kickbush 1981) and involves the health professional taking on more of an educative and supportive role.

However, little research has been done in this field. Whilst there is some evidence to suggest that patients and relatives and nurses feel positive about the concept of lay participation in care (Brooking (1986); there is also a need to investigate the opinions and responses of other health professionals in the multidisciplinary team. Furthermore no

research has looked at the implications of increasing lay participation in care within a hospital. By using evaluation strategies and an action research approach, the impact of this change in care will be monitored. Questions should be answered about the degree of success of the innovation and the processes involved. By giving a sufficiently detailed and illuminating description of the facts, problems, issues, experiences and perceptions, others might be in a position to judge their application to themselves.

Related Research

Brooking (1986) examined patient and relative participation in nursing care and found to be lacking. None of the wards studied had policies (formal or informal) on patient and family participation in care. Learners were not taught about this type of care and there was little evidence of any participation in practice. These findings emerged despite the nurses, patients and relatives showing positive feelings towards the concept.
Little research has looked at the attitudes towards lay participation in care. Likert-type attitude scales have been used with physicians (Linn and Lewis 1979) and nurses (Pankratz and Pankratz 1974) but the limitations of such quantitative measures should be noted.

A number of studies have shown beneficial effects from giving patients and their relatives more control over care (e.g.. Schulz 1976). However, there is a paucity of research which examines the relative's perspective of care. The need for qualitative data in this field has been recognised (Brooking 1986, Batehup (1987).

Hamilton (1976) reviewed the trends in the evaluation of change. He identified the recent changes in style and method in evaluation as moving away from the 'agricultural model' towards the 'anthropological model'.

The agricultural method describes studies designed to yield 'objective' numerical data that permit statistical analyses. Typically variables are isolated and measured to determine the success of a particular innovation. Parlett and Hamilton (1972) note several difficulties with this approach. Either the study has to be strictly controlled for affecting variables or very large samples and randomisation needs to be used. The former creates an artificial setting and inhibits results being generalised to an "untidy" reality. The latter creates a major data collection which is both expensive in both time and resources.

Before-and-after designs are also not appropriate with innovatory programmes as they discourage new developments and redefinition mid-stream. Furthermore by concentrating on quantitative information the 'subjective' 'anecdotal' or 'impressionistic'

is disregarded. There is also a tendency to ignore atypical results in the agricultural method which may well have a direct effect on the outcomes. Such an approach also fails to deal with the questions and influences of participants, sponsors and other interested parties. In preference to the agricultural method, Parlett and Hamilton (1972) advocate the anthropological method i.e.. illuminative evaluation. Its primary concern is with description and interpretation rather than measurement and prediction. An example of an innovatory programme in nursing which was evaluated using illuminative evaluation strategies, was 'The Ward Sister Training Project' (Lathlean and Farnish 1984).

Illuminative evaluation can occur within the framework of action research. Actin research emphasises the collaborative relationship between the research and those people in the setting where the research takes place. It involves a problem solving approach and requires a commitment for change. Action research aims to establish an infra structure within the social system which continues to maintain and develop the innovation once the researcher has withdrawn. Susman and Evered (1978) assessed the scientific merits of action research and concluded that it was not compatible with the criteria for scientific explanation as established by positivist science. They argue: "action research constitutes a kind of science with a different epistemology that produces a different kind of knowledge, a knowledge which is contingent on the particular situation and which develops the capacity of members of the organisation to solve their own problems.....as a procedure for generating knowledge, we believe it has far greater potential than positivist science for understanding and managing the affairs of organisations". pg. 601. Pasmore and Friedlander (1982) showed how an action research intervention succeeded where traditional methods failed.

Few action research studies have been carried out in nursing though it has been advocated as a means of facilitating the use of research findings in practice (Greenwood 1984).

Aims and Objectives

The aim of this project is to describe the process and impact of introducing lay participation in care within the care environment.

Objectives

1. To ascertain what is understood by lay participation in care.

2. To establish which wards wish to participate in an action research study aimed at introducing lay participation in care.

3. To describe how patients, their close relatives and friends plus health professionals feel about lay participation in care.

4. To determine how lay participation in care can be systematically introduced in a ward environment.

5. To identify the effects of introducing lay participation in care in a ward environment.

6. To consider whether any specific groups of patients respond better to lay participation in care e.g.. age, sex, culture, disease processes, social class and education.

7. To monitor the changing roles of health professionals on introducing lay participation in care.

8. To specify the effects of introducing lay participation in care on the wider environment of the hospital.

9. To highlight the implications of introducing lay participation in care within a ward environment for community care following discharge.

Population and Research

Two wards within a London teaching hospital. The hospital has been chosen because of the researcher's previous work within the organisation (Ward Sister - 5 years before). It is envisaged that familiarity with the general environment will enhance the acceptance of the researcher by the multidisciplinary ward teams and lead to closer collaborative relationships (essential in action research).

The wards will be selected for their interest in lay participation in care and willingness to work with the researcher as a welcomed member of the ward team.

Data will be gathered from the multidisciplinary team members (doctors, nurses, physiotherapists, occupational therapists, social workers etc.).

Data will also be gathered from patients, relatives and their significant others during their hospital stay and possibly after discharge.

Design

Phase 1 - Negotiation

The researcher has been given an honorary contract to work as a research nurse within the Health Authority and is currently negotiating access to wards within the hospital. All charge nurses of adult patients have been interviewed to ascertain their interest in lay participation in care and willingness to take part in an action research study. From this initial survey of the hospital, 6 wards have been identified and discussions are now taking place between the researcher and the consultants of these wards. Acceptance and commitment to the research ideas must be obtained from all the multidisciplinary team members before the innovation can begin. It is proposed that the researcher spends time working with the multidisciplinary team on a ward for a week to negotiate access and establish interest in the research itself. It should be stressed that at any stage the multidisciplinary team feels the researcher is no longer welcome as a member of the team, the researcher will willingly leave (action research depends upon collaboration between the researcher and client). The researcher would, however, wish to document the reason for her departure which would be viewed as a finding in itself. The researcher would then re-negotiate access to another ward. It is anticipated that the researcher will work on one ward for 6 months in the role of researcher-facilitator. Following this a further 6 months will be spent on another ward in the same role. However, if after 6 months it was decided by the multidisciplinary team that insufficient had been achieved, the researcher would negotiate staying on for longer. In this case the research would consist of one in-depth case study as opposed to two case studies.

Phase 2 - The Context

An assessment of the ward environment will be made before and after the innovation. Qualpacs may be used as a measure of quality assurance Wandelt et al (1974). Other measures might also include:-

1. Patient and family participation Scale. Brooking (1986).

2. Measurement of ward sister performance in relation to individualised nursing. Pembrey (1980).

3. The ward teaching environment. Fretwell (1980).

4. Nursing Process Measurement Scale. Brooking (1986).

It is anticipated that the introduction of lay participation in care implies a change in role for the health professional; there will also be changes in the ward environment which it would be useful to monitor.

Phase 3 - The Innovation

The researcher will work as a research nurse in the role of facilitator on the ward. Initially in-depth interviews with the multidisciplinary team and possibly some patients and relatives after discharge will occur. This should highlight what is understood by lay participation in care, how people feel towards the concept and what they would like to innovate. The researcher will then facilitate these innovations in practice. For example, if the multidisciplinary team identify that patients should have more control for their drug taking whilst in hospital because of the problem of non-compliance after discharge, then the researcher will look into the feasibility of putting this change into practice.

The researcher will attend ward rounds, ward reports and ward meetings and aim to focus attention on lay participation in care.

The researcher will work on a one to one level with the qualified members of staff focusing on lay participation in care with selected patients. The patients will be selected by the qualified nurses; initially each qualified nurse will be encouraged to concentrate on one patient but later as confidence develops other patients might be included. The qualified nurses and patients will constitute smaller case studies within a larger case study. The researcher will not take responsibility for the nursing care of any group of patients but will work intensively with the nurses allocated to them in an educative and supportive role.

Phase 4 - The Evaluation

The Evaluation will be formative in nature with regular feedback to the multidisciplinary team to encourage changes in mid-stream. The fact that the researcher will also be involved in facilitating the innovation is not considered to be a problem. Illuminative evaluation accepts that subjectivity exists in any research design. It is thought that by combining both roles of researcher and facilitator, a more intimate and realistic understanding of the context and the process of the innovation will be obtained.

Action research aims to set up infra structures within the social system so that the innovation is maintained in the absence of the researcher. A later evaluation (8 months) will take place to assess whether the innovation occurred as a result of the presence of a facilitator or whether the system has maintained the concepts in practice.

Instrumentation and Data Collection

Data will be collected to highlight the problems and issues of introducing lay participation in care within the ward environment.

Data will be gathered from:

Doctors
Nurses
Occupational Therapists
Patients
Pharmacists
Physiotherapists
Relatives and Significant others
Speech Therapists
Social Workers

Data may also be gathered from others who emerge as being significant during the innovation.
A variety of research methods will be employed capable of describing the process of the innovation as well as the outcome.

Observation

Continuous record of ongoing events, transactions and informal remarks will be kept in the researcher's diary.

Observation of nursing records to monitor changes in documentation of lay participation in care.

Interview

It will not be possible to interview every participant at each stage of data collection. Interviewees will be selected either randomly or by theoretical sampling (Glaser and Strauss 1967). This latter mode requires seeking out informant or particular groups who have special insight or whose position makes their viewpoints noteworthy.

Interviews will make use of "open-ended" questions to give respondents freedom to express their opinions. Audio tapes will be used to record the data.

It may be possible to record some in-depth group discussions, when multidisciplinary team members meet to discuss patient care.

Measurement Scales

Non invasive measurement tools may be used to substantiate data gained through qualitative methods. Jick (1979) argued the need for triangulation of data to include quantitative and qualitative material.

Data Analysis

It is not possible to anticipate the complete nature of the data and hence the analysis of the data when inductive qualitative data is being carried out. Lathlean (1984) describes the use of 'Analytic Induction' in such a situation. Denzin (1970) describes 'Analytic Induction' as appropriate when "a rough definition and hypothetical explanation of a phenomenon was already available from previous observations. Instances or cases, were then examined to see if the facts fitted the 'hypothesis'. If not, either the hypothesis was reformulated or the phenomenon to be explained was redefined. This was continued until a universal relationship (between the facts and the hypothetical explanation) was established". Denzin (1970)

As described previously the methodology in this project follows an anthropological method. It concentrates on the 'subjective' 'anecdotal' and 'impressionistic' views in order to gather qualitative data. It tends not to yield 'objective' numerical data that permit statistical analyses.

Work Plan

Phase 1	-	**Negotiation**
March 1988	-	Interview nursing hierarchy
April 1988	-	Interview ward sisters
May 1988	-	Interview consultants
June 1988	-	Work as member of ward team to negotiate access and feasibility of study.
Phase 2	-	**Context**
July 1988	-	Assess ward environment

Phase 3	-	**The Innovation**
August 1988 September 1988	))	Interview multidisciplinary team and some patients and relatives after discharge
October 1988	-	Feedback findings to multidisciplinary team and establish policy for lay participation.
November 1988 February 1989	))	Facilitate lay participation in care working with cohort of qualified nurses
Phase 4	-	**The Evaluation**

Data is gathered throughout the evaluation and fed back to multidisciplinary team.

March 1989	-	Reassess need to continue as facilitator.
April 1989	-	?Move to new area and restart process of negotiation.
May 1989 October 1989	))	Facilitate lay participation in care on new ward
November 1989	-	Re-evaluate original ward to assess if infra structure has maintained the innovation.
December 1989 July 1990	))	Analysis of data and report writing
August 1990	-	Re-evaluate 2nd ward to assess if infra structure has maintained the innovation.
September 1990 October 1990	))	Analysis of data and Report Writing

Expected End Product

Final Report.

Ward Philosophy on lay participation in care.

Infra Structure for ensuring lay participation continues in absence of researcher.

Ethical Considerations

An honorary contract has been given by the nursing hierarchy for the investigator to work as a research nurse in the health authority until the completion of her studies. The researcher is directly answerable to the Director of Nursing Services with whom she shall have regular contact for support and feedback.

Action research depends upon collaboration between the researcher and the client. Careful and thorough negotiations have been used to identify those wards interested in participating in the study. The researcher is willing to leave a ward should the multidisciplinary team become uncomfortable in her presence.

Patients will be informed by letter on admission that research into lay participation in care is being carried out on the ward. It will be stressed that patient and family participation in care will be more appropriate for some patients than others and that there is no obligation for any patient to take part in this type of care unless they wish to do so.

Verbal consent will be obtained from all respondents who are interviewed in hospital. Written consent will be obtained from patients and relatives interviewed at home following discharge.

Interviews will be tape recorded. Respondents will be encouraged to volunteer frank and honest responses but assured of confidentiality. The possibility of erasing tape material if desired will be offered.

Regular feedback should ensure that any problems and difficulties which arise during the innovation will be dealt with according to the multidisciplinary team's wishes.

Sensitivity in reporting will be essential. This does not imply that finding would go unreported but that respondents must be involved in discussing findings so as not to feel betrayed.

Confidentiality will be assured. Respondents will not be named in the report. However, discussions concerning the publication of findings will take place to safeguard individuals who may be concerned that they may be recognised in the case studies.

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APPENDIX XII

PHASE 2 - INITIAL INTERVIEW SCHEDULE FOR MULTIDISCIPLINARY TEAM

Introduction

As you know, I'm involved in a research study which is aimed at identifying the problems and issues of getting patients and their close family and friends more involved in care on the ward (lay participation in care). I am interested in your thoughts on this subject.

Willing to be interviewed Yes/No
Willing to be taped Yes/No

Cover following points
- confidentiality and anonymity
- can stop the tape recorder at any stage
- can erase the tape at any stage
- will be given transcript for any desired alterations

1. Tell me a little bit about yourself
   e.g. where you trained
   how long you have been qualified
   where you have worked in the past

2. Have you had any previous experience of trying to involve patients and their family and friends in care?

3. How do you feel about patients and their family and friends getting more involved in care on the ward?

4. What do you see are the advantages and benefits of this type of care for:
   - patients
   - family and friends
   - health professionals

5. What do you see are the disadvantages of this type of care for:
   - patients
   - family and friends

- health professionals

6. As you know I intend to feedback my findings to the multidisciplinary team with a view to changing practice on the ward and monitoring these changes.

   Do you think the ward is ready for change? Why?

7. What difficulties do you think might be encountered in making these changes?

8. What changes would you like to see made which would involve patients and their family and friends in care in hospital?

9. Can you think of any particular patients on the ward at the moment who would benefit from this type of care in hospital?

10. Can you think of any particular patients on the ward at the moment who would not benefit from this type of care?

11. Have you any experience of yourself or of a member of your family and friends being admitted to hospital? Yes/No

    What aspects of care (if any) were you allowed to participate in?
    What aspects of care (if any) would you have liked to be more involved in?
    What aspects of care (if any) would you not have liked to be involved in?

12. Can you think of anything else you would like to say on the subject?

Cover following points:

Thank you for participating
Results will be fed back anonymously to the multidisciplinary team
Transcripts will be returned for any desired alteration (amendments and additions)
Will not share findings that multidisciplinary team do not wish to be shared

Rationale for Questions Asked

The first question asked aimed to put the participants at ease by getting them to speak in general about themselves. It was also useful to have an idea of their work experience given that I was going to be a fellow member of the multidisciplinary team. The second question enquired after any previous experience of lay participation in care and was asked to determine to what extent individuals had worked previously with the concept. The third question explored in general terms how participants felt about lay participation in care. It was followed up by two further questions which asked for more specific views by identifying the advantages and disadvantages from a range of perspectives (patient, family and friends and health professional). Thus the three questions focused on the participants' perceptions of lay participation in care. The sixth question invited participants to comment generally on whether they thought the ward was ready for change. This was followed by a more specific question asking participants to consider what difficulties might be encountered on the ward when trying to change practice. Given that this was an action research study I felt it was important to anticipate what might need to be taken into account when trying to change practice. The eighth question invited participants to identify what changes they would like to make on the ward so that patients and their family and friends might be more in control of their care on the ward. This was asked so that a draft ward policy on lay participation could be based on the participants' own ideas for change. In action research it is important that participants collaborate with the change and a "bottom up" approach rather than a "top down" approach is considered more likely to encourage collaboration. The suggestions for change formed the basis of planning discussions for change amongst the multidisciplinary team.

The next two questions asked participants to consider whether any particular patients would benefit or not benefit from such an approach to care. They were asked for two reasons. First, if a specific group of patients emerged as being highly suitable, the multidisciplinary team may have chosen to concentrate on this group of patients whilst changing practice in the first instance. Second, patients thought not to be suitable for this form of care could be avoided. Participants were asked to focus on patients on the ward at the time of the interview to encourage them to think about the concept in real terms. The penultimate question then asked participants to reflect on their own personal experience of either being a patient or of knowing someone close to them who had been hospitalised. They were asked to recall whether they or their close family and friends had been involved in care during that period of hospitalisation and the extent to which they would have liked more, or less, participation in care. The question enabled participants to think again about the concept of lay participation in care from the angle of the recipient of

care rather than from the professional perspective. For some participants this was quite challenging and gave them some interesting insights into what it might feel like to be a patient in hospital or a close family member or friend of someone in hospital. Finally a general question was asked to see if the participants had anything else they wanted to add which that had not been addressed during the interview.

APPENDIX XIII

PATIENT AND FAMILY PARTICIPATION IN CARE SCALE

QUESTIONNAIRE FOR NURSES

Brooking (1986)

Nurses' Questionnaire

HOW YOU ORGANISE THE CARE OF YOUR PATIENTS

Please tick one column for each question. If you do not currently work in direct patient contact, please answer as you would if you were working on a ward.

When I am caring for a patient:	Never	Sometime	Often	Always
1. I plan the nursing care without asking the patient's family what they think.				
2. I tend to do everything for my patients, even if they could manage themselves.				
3. I discourage the family from doing anything for the patient while he/she is in the care of the hospital.				
4. I encourage the patient to express his/her views when decisions about his/her nursing care have to be made.				
5. I encourage the relatives to help with the patient's nursing care in various ways.				
6. I encourage my patients to be as independent as possible and help themselves as far as their illness allows.				
7. I try to consult the relatives when decisions about the patient's care have to be made.				
8. I try to decide what needs to be done for the patient without asking his/her views.				

IF YOU WISH TO MAKE ANY GENERAL COMMENTS, PLEASE USE THE OTHER SIDE OF THIS SHEET OF PAPER.

Nurses' Questionnaire

CARE ACTIVITIES IN HOSPITAL

Below is a list of some activities which may be required by patients. Please decide whether, in your opinion, each activity could be carried out by a nurse, the patient himself or the patient's relative. Tick at least one column for each item. However, you may tick several columns if more than one answer seems to be appropriate.

	The following activities could be done by:	Nurse	Patient	Relative
1.	Filling in the fluid chart			
2.	Applying ointment to the patient's skin			
3.	Dressing or undressing the patient			
4.	Cleaning the patient's teeth or mouth			
5.	Bringing or removing bedpan or bottle			
6.	Taking the pulse			
7.	Helping the patient to eat or drink			
8.	Brushing the patient's hair			
9.	Helping the patient to walk to the toilet			
10.	Testing the urine			
11.	Giving an injection			
12.	Rubbing the patient's back or bottom			
13.	Giving a suppository			
14.	Tidying the bedclothes or pillows			
15.	Washing the patient in bed			
16.	Helping the patient in or out of bed			
17.	Making him/her comfortable in bed or chair			
18.	Putting in ear-drops or eye-drops			
19.	Assisting him with bathing			
20.	Taking the temperature			

IF YOU WISH TO MAKE ANY GENERAL COMMENTS, PLEASE USE THE SPACE BELOW:

In this section please tick whichever of the five columns best describes your view of the previous statement. Remember there are no right or wrong answers. I am simply interested in your personal opinion.

	Strongly Agree	Agree	Disagree	Strongly disagree
1. The essence of nursing is doing things for people to people to enable them to rest and relax in hospital.				
2. When a patient is first admitted, the nurse should ask him which of his problems and needs he regards as most important.				
3. Relatives have a right to know what is being done to their 'nearest and dearest' by the nursing staff.				
4. When nurses are considering what is best for a particular patient, they should ask him what he prefers.				
5. Information from a spouse about the patient's normal life style helps nurses to assess what care will be required.				
6. If patients are well enough they should be allowed to keep their own medicines in their lockers and take them as prescribed.				
7. Patients must accept that whilst in hospital they have no right to question nurses' decisions about what needs to be done to them.				
8. Nurses should encourage patients to be as independent as possible.				
9. Even if it would be quicker for a nurse to dress an elderly lady, she should try to encourage the old lady to do it herself.				
10. Patients who are well enough should be allowed to write up their own charts of how much fluid they are drinking each day.				
11. Before an operation the implications and risks of surgery should be discussed with the patient's nearest relative.				

12. Patients are entitled to do things for themselves as long as they feel they are well enough and provided it is medically safe.				
13. It is up to the nurses to assess how often patients need to wash their hair whilst in hospital.				
14. It is always the nurses responsibility to decide on the most suitable time to renew a patient's bandage.				
15. Relatives must accept that they are not entitled to do anything for the patient while he is the responsibility of the hospital.				
16. If a patient has a skin disease, the nurse should apply the ointment to ensure that it is rubbed in properly.				
17. As far as possible, patients should be allowed to decide for themselves when they want to wash and bath.				
18. It will only lead to problems for the nurses if relatives are allowed to do too much for the patient				
19. If a patient is going to need care at home, the nurses should teach his wife how to look after him while he is still in hospital.				
20. When a child is in hospital his mother should be encouraged to wash and feed him, provided that it is medically safe.				
21. Relatives must accept that nurses have the training and experience to assess the patient's needs without interference from the family.				
22. It is good for both patients and nurses if relatives can help with simple tasks like giving the patient a cup of tea.				
23. In planning a course of rehabilitation after a stroke, the nearest relatives should be invited to contribute their ideas.				
24. Most patients are happy to hand over to the nurses complete responsibility for deciding what care they require.				

Nurses' Questionnaire

In your opinion, what is the effect of the nursing process on each of the following? Please tick one column for each question. There are no right and wrong answers.

	Very good	Good	No effect	Bad	Very bad
1. Patients' emotional well-being					
2. Nurses' learning opportunities					
3. The nurse-patient relationship					
4. The doctor's work					
5. The overall standard of nursing care					
6. Sisters' job satisfaction					
7. Ward atmosphere and morale					
8. Patients' physical well-being					
9. Relatives' contentment and well-being					
10. Nurses' job satisfaction					
11. Time spent on paperwork					

IF YOU WOULD LIKE TO MAKE ANY GENERAL COMMENTS ON THE NURSING PROCESS PLEASE USE THE SPACE BELOW:

What changes would you like to see made on X Ward which would encourage patients and their supporters (friends/relatives) to be more involved in their care in hospital?

Any other comments?

Nurses' Questionnaire

Some questions have boxes: ☐ Tick the one box which is most appropriate for you.
Some questions have lines:_____Write your answer on this.

FOR WARD-BASED NURSES ONLY:

How much time have you spent working on the wards in which the nursing process was used?

- None ☐
- Less than 2 months ☐
- 2-6 months ☐
- 7-12 months ☐
- More than a year ☐

FOR NURSING OFFICERS AND ABOVE ONLY:

How long have you been directly concerned with the nursing process in your unit or area?

- None ☐
- Less than 2 months ☐
- 2-6 months ☐
- 7-12 months ☐
- More than a year ☐

FOR ALL NURSES:

Have you read any books or articles about the nursing process?

- No ☐
- One or two ☐
- Three or more ☐

In your current position, are you encouraged to read about the nursing process?

- No, not really ☐
- Yes, to a certain extent ☐
- Yes, very much ☐

Have you attended any lectures, study days, discussions or seminars on the nursing process?

- No ☐
- Yes, one ☐
- Yes, several ☐

Nurses' Questionnaire

OFFICIAL POLICIES TOWARDS SOME NURSING ISSUES

in this section, please give as much detail as you can. If you do not know, or have never been informed about this policy, please indicate that in your answer.

ISSUE ONE: THE PARTICIPATION OF PATIENTS IN THE PLANNING OF NURSING CARE.

a) What is your ward, unit or area policy towards the above issue?

b)What , if anything, are nurses in training taught about the above issue?

ISSUE TWO: THE PARTICIPATION OF RELATIVES IN THE PLANNING OF NURSING CARE.

a) What is your ward, unit or area policy towards the above issue?

b)What , if anything, are nurses in training taught about the above issue?

ISSUE THREE: THE EXTENT TO WHICH PATIENTS ARE ENCOURAGED TO ASSIST WITH THEIR OWN NURSING CARE.

a) What is your ward, unit or area policy towards the above issue?

b)What , if anything, are nurses in training taught about the above issue?

ISSUE FOUR: THE EXTENT TO WHICH RELATIVES ARE ENCOURAGED TO ASSIST WITH THEIR OWN NURSING CARE.

a) What is your ward, unit or area policy towards the above issue?

b)What , if anything, are nurses in training taught about the above issue?

You have finished now. Thank you very much for filling in this questionnaire. I hope that the findings of this study will help our knowledge of patient care in hospital.
Could you please have a quick look over your forms to make sure you haven't missed out any questions.
Finally, I should be grateful for a few personal details. These, of course, will be treated in complete confidence.

Are you: ☐ ☐

How old are you? 18-34 ☐ 35-51 ☐ 52-68 ☐

Are you:
- Single ☐
- Married ☐
- Widowed, separated or divorced ☐
- Other (please specify) ☐ _____

Is you occupation:
- Working full-time ☐
- Working part-time ☐
- Student ☐
- Housewife ☐
- Retired ☐
- Unemployed ☐

If working, please name your job:_____

_____

Please describe your duties in your job:_____

_____

_____

If you have a spouse who is working, please name his/her job:_____

_____

If you have a spouse who is working, please describe his/her duties in the job:_____

_____

_____

Please list any educational qualifications you have:_____

_____

Please list any professional or technical qualifications you have:_____

_____

What is your nationality?_____

_____

Where were you born?_____

APPENDIX XIV

WARD LEARNING ENVIRONMENT RATING SCALE

Rating Questionnaire for Learners

Ward..... Nurse Number.....

Year of Training When on Above Ward.....

The following statements are concerned with nurse training in the ward situation. For each group of statements, please ring the letter (a, b, c, or d) of the statement which is closest to your own view e.g.. a. Ring ONE letter for each group. YOUR opinion is what matters, so please indicate your view for all questions.

1. a. There was very much to learn on this ward.
   b. There was a lot to learn on this ward.
   c. There was quite a lot to learn on this ward.
   d. There was hardly anything to learn on this ward.

2. a. The doctors were definitely not interested in teaching nurses.
   b. The doctors were really not interested in teaching nurses.
   c. Some doctors were quite interested in teaching nurses.
   d. Some doctors were very interested in teaching nurses.

3. a. Not many learners would benefit from working on this ward.
   b. I don't really know if other learners would benefit from working on this ward.
   c. I think most learners would benefit from working on this ward.
   d. I think all learners would benefit from working on this ward.

4. a. The qualified nurses taught me many things.
   b. The qualified nurses taught me a lot of things.
   c. The qualified nurses taught me quite a lot of things.
   d. The qualified nurses hardly taught me anything.

5. a. There was always someone to supervise new procedures.
   b. There was usually someone to supervise new procedures.
   c. There was sometimes someone to supervise new procedures.
   d. There was rarely anyone to supervise new procedures.

6. a. I learnt little on this ward.
   b. I learnt quite a lot on this ward.
   c. I learnt a lot on this ward.
   d. I learnt very much on this ward.

7. a. Clinical teachers taught frequently on this ward.
   b. Clinical teachers taught sometimes on this ward.
   c. Clinical teachers hardly ever taught on this ward.
   d. Clinical teachers never taught on this ward.

8. a. This is the best ward I have worked on.
   b. This is one of the best wards I have worked on.
   c. This ward is no worse and no better than other wards I have worked on.
   d. This is one of the worst wards I have worked on.

9. a. I did not like working on this ward.
   b. I did not mind working in this ward.
   c. I liked working on this ward.
   d. I liked working on this ward very much.

10. How did you feel about working on this ward?

11. How did you feel about the patient care on this ward?

12. In what ways was the patient care different to the other wards you have worked on?

APPENDIX XV

THE NURSING PROCESS MEASURING SCALE (BROOKING 1986)

Ward Nurses' Self-rating Scale

The scale measures how much nursing process is being used in one ward. It is not a test of your knowledge or practice and there are no right or wrong answers. Your name is not required and your answers will be entirely confidential. Please answer each question in relation to your own experience on this ward. Please tick one box for each question.

What is the name of this ward? .....

How long have you worked on this ward? .....

What is your current grade?

sister/charge nurse ☐
staff/enrolled nurse ☐
student/pupil nurse ☐

Please list any educational qualifications you have .....

Please list any nursing or other professional qualifications you have .....
.....

What is today's date? .....

		yes, always/ excellent	yes, usually/ good	yes, often/ fair	some times/ poor	don't know	no, never
1.	Is an assessment made of new patients, prior to planning and giving care?						
2.	Is a written nursing history taken, using a specific form?						
3.	Does the nursing assessment begin within 24 hours of admission?						
4.	Are nursing problems identified and written down for all new patients?						
5.	Are potential and/or possible problems identified as well as actual problems?						
6.	Is an attempt made to find and record the causes of patients' problems?						
7.	Are problem statements arranged in order of priority?						
8.	Are problem statements made with the knowledge and agreement of patients and/or relatives?						
9.	Are written care plans produced which incorporate patients' problems and/or needs?						
10.	Are care plans up dated daily?						
11.	Are nursing care planning discussions or rounds held on the ward?						
12.	Do care plans include discharge planning?						
13.	Are goals (nursing objectives) incorporated into the care plans?						
14.	Do the goals include both long and short term goals?						
15.	Are goals agreed upon with patients and/or relatives?						
16.	Are goals written in terms of patient outcomes i.e. change in the patient?						
17.	Do goals specify a time element for achievement?						
18.	Are problem-oriented planned nursing actions included in care plans?						
19.	Are planned nursing actions agreed upon with patients and/or relatives?						
20.	Are planned nursing actions written in detail?						
21.	Are patient allocation or primary nursing used throughout the ward at all times?						
22.	Are nurses allocated to the same patients for several days?						
23.	Are care plans used for the verbal ward handover reports?						
24.	Are written nursing progress reports based on patients' problems and goals?						
25.	Are nurses responsible for written and verbal reports on their patients?						
26.	Do nurses take part in medical rounds for their patients?						
27.	Are care plans used both day and night as a basis for giving care?						
28.	Is systematic evaluation of care carried out for all patients?						

		yes, always/ excellent	yes, usually/ good	yes, often/ fair	some times/ poor	don't know	no, never
29.	Is evaluation recorded on the care plans or progress notes?						
30.	Are dates for the evaluation of patients' problems included in the care plans?						
31.	Are objective measures of patient progress used on the ward?						
32.	Are patients and/or relatives included in evaluation?						
33.	Are care plans modified according to the results of evaluation?						
34.	Have study days or lectures been held to teach nursing progress to permanent ward nurses?						
35.	Have all permanent ward nurses attended at least one study day or lecture on nursing progress?						
36.	Is nursing process taught to learners in the school of nursing?						
37.	Does the sister/charge nurse involve nurses in decision-making and delegate responsibility?						

IF YOU WISH TO COMMENT ON THE USE OF THE NURSING PROCESS IN THIS WARD, PLEASE WRITE ON THE BACK OF THIS FORM:

APPENDIX XVI

PHASE 4 - EXIT INTERVIEW SCHEDULE FOR MULTIDISCIPLINARY TEAM

Introduction

As you know I'm involved in a research study which is aimed at identifying the issues and problems of involving patients and their close family and friends more in care in hospital (lay participation in care). Before you leave the ward/Now that the study is coming to an end, I want to explore your feelings about the project ideas and examine what changes, if any, have taken place on the ward to encourage lay participation in care. Given that lay participation is being advocated as an approach to care, I want to look at the issues of trying to put this approach into practice. I want you to feel able to give honest responses to the questions as it is more important and helpful to share with others the reality of what happened.

Willing to be interviewed Yes/No
Willing to be taped Yes/No

Cover following points
- confidentiality and anonymity
- can stop the tape recorder at any stage
- can erase the tape at any stage
- will be given transcript for any desired alterations

1. Tell me about why you are leaving the ward
   e.g. how long have you worked there?
   why are you now leaving?
   where are you moving on to?

2. What is meant by lay participation in care?

3. How do you feel about patients and their family and friends getting more involved in care on the ward?

4. What changes, if any, have been made on the ward to facilitate lay participation in care that you regard as working successfully?
   - how do you feel about this?

5. What changes, if any, have been made on the ward to facilitate lay participation in care that you do regard as **not** working successfully?
   - how do you feel about this?

6. What changes, if any, would you have liked to make on the ward that have not been achieved?
   - how do you feel about this?

7. What difficulties do you think have been encountered trying to make these changes?
   - how do you feel about this?

8. Which patients, if any, have been more involved in care as a result of the project?

9. How do you feel about having had me as an action researcher working on the ward?

10. Can you think of anything else to say either about lay participation in care or about the research project on the ward?

Thank you for participating
Results will be fed back anonymously to the multidisciplinary team
Transcripts will be returned for any desired alteration (amendments and additions)
Will not share findings that multidisciplinary team do not wish to be shared

APPENDIX XVII

QUALITATIVE DATA ANALYSIS PROCEDURE

Introduction

The approach taken to the qualitative analysis of the interview data was that advocated by (Miles and Huberman, 1984). Their stance is that social phenomena exist not only in the mind but in the objective world. They argue that phenomena exist objectively in the world because people construe them in common or agreed-upon ways, so these perceptions are crucial in understanding why social behaviour takes the from that it does. For Miles and Huberman the task in qualitative data analysis is to express these social regularities as precisely as possible, attending to their range and generality and to the local and historical contingencies under which they occur. They place considerable emphasis on the importance of evolving a set of valid and verifiable methods for capturing these social relationships in order that others using the same tools would arrive at analogous conclusions. Thus Miles and Huberman are committed to clarity in qualitative analytic procedures requiring the researcher to be explicit about the structure of the analysis itself. They suggest that the analysis of qualitative data consists of three concurrent flows of activity: data reduction, data conclusion and conclusion drawing and verification. Data reduction consists of the process of selecting, focusing, simplifying, abstracting, and transforming the "raw" data. This appendix will make explicit how the interview data were reduced in this study.

Stage 1

Interview data were transcribed and initially notes were made in the margin highlighting issues and points being made in response to questions asked (see Example for Stage 1). This analysis remained very much at the level of description rather than interpretation and could best be described as a manifest analysis as opposed to a latent analysis (Fox, 1976). Given that the purpose of these interviews was to feedback findings to the participants in order that they could make decisions about what they may want to change in practice, it seemed important to be descriptive rather than interpretive at this stage. Interpretation would have involved me imposing my own views to a certain extent and in action research it is important to allow the participants to lead the project and act as a facilitator rather than leader of change.

Stage 2

Once all the transcripts had been analysed in this way, the issues and points being raised were compiled under the headings of the questions asked for each individual (see Example for Stage 2). Whilst the interviews were semi-structured all the questions were open ended and participants were encouraged to talk about whatever they thought was relevant to the topic. This meant that often comments would be raised at different points of the interview (sometimes even after the interview appeared to have finished). In these circumstances, these comments would just be added under the heading of the appropriate question previously asked. Furthermore sometimes answers given were relevant to more than one question asked and again the comment was included in both or more places where appropriate.

Stage 3

Next an amalgamation of these issues and points occurred under the headings of the questions asked, in such away, that it was possible to note who and how many participants had raised which issue and point (see Example for Stage 3). At this stage, whilst the data were being systematically organised, it was not being reduced and thus visual records exist to substantiate the findings which clearly indicate the process of analysis. A decision was taken to enumerate how many participants raised which issue but attention was given not to loose the quality of the data. For instance it was recognised that one person may be particularly articulate and insightful and be able to make comment on something that whilst not being raised by other participants was nonetheless significant. By using this method of data reduction no issues raised were ignored but it was felt to be useful to comment on the added dimension of how many people had thought to identify specific points. This was especially thought to be of interest to the participants who would be basing their decisions to change practice on the basis of feedback of these findings. The quantification may have helped them to ascertain which issues were of particular immediate importance to the whole team in terms of changing practice. The quality of the data was also ensured by the keeping of quote cards on each participant (see Example of Quote card). As the transcripts were read on repeated occasions to ensure familiarity with the data, if an individual clearly illustrated an issue or point being raised, it was highlighted in colour on the transcript and a note of the issue being discussed was made on the individual's quote card giving the appropriate transcript page number to refer to a later date. In this way a systematic approach to retaining the quality of the final presentation of the data would be ensured by having easy and ready access to illustrative comments.

Stage 4

Next the points and issues raised were transferred to a computer and by means of a word processing package it was possible to group issues raised into themes for each question, taking account of how many times each point was raised by which professional group (nurse, medical staff, paramedical staff and joint team response). These figures were then converted into percentages for each group. Thus the data started to be reduced into themes but again a visual representation was made to demonstrate how these issues and points had been grouped together.

The grouping of issues and points into themes were then ordered in importance based on the joint team response. Using different coloured highlighter pens those issues and points being raised by more than 25% of participants in any on group, more than 50% of participants in any on group and more than 75% of participants in any on group were identified. In presentation of the data, a decision was taken to describe all the themes identified for each question asked. Some miscellaneous comments which did not group into themes were discarded at this stage but could be easily visually identified if required. Furthermore in terms of presentation of the data it was decided to focus on those issues and points being raised by more than 25% of participants and to particularly mention those issues being raised by more than 50% of participants and to especially comment on those points being raised by more than 75% of participants.

In this way the data were systematically analysed and reduced into themes whilst making explicit all the stages of analysis. Whilst some attention was paid to enumerating the responses, this was seen as adding a dimension as opposed to detracting from the qualitative data. At the end of the analysis it was possible to demonstrate how each theme had been developed even to the point of identifying which individuals had contributed to it. Furthermore it was possible to easily demonstrate any of these points with an illustrative quote. Nothing was left to memory the data were systematically and rigorously analysed in line with the requirements of (Miles and Huberman, 1984).

Stage 1 Example: Transcript of one of the nurses' initial interviews

J Right if you'd like to tell me a little bit about yourself, where you trained, how long you've been qualified and where you've worked in the past.

N5 Well I trained in R at the RB Hospital and I finished my training in November '86 and I left straight away and six

2yrs

months in a ski resort I then came back and did five or six months agency nursing around London, and then in October last year I went to India and did four months voluntary nursing in Calcutta, and then travelled for three months and then I came back March this year and started working.

Royal Beeks
skiing
agency
voluntary
travel
6 mths - work

J Right, have you had any previous experience of trying to involve patients and their family and friends in care in hospital?

N5 Well probably just on one ward that I worked which was mainly for chemotherapy and radiotherapy patients and I found that their relatives did take part in their care a lot more than on a general ward.

Chemotherapy
Radiotherapy

J Right, what particular aspects of care?

N5 Really just washing the patients and feeding the patients, noting specific

washing
feeding

J Have you had any other experiences of patients and their relatives and friends getting involved in care?

N5 I mean once of twice..... I mean odd cases but not as the norm on a general ward, no.

odd cases

J Odd cases, ... can you remember any of the odd cases?

N5 Um ..... not really ..... well on orthopaedics we had a very young chap who was eighteen who had had a motor bike accident and the doctors had given up and thought that he was irreparably brain damaged, probably wouldn't survive and hid relatives more or less took over all his care and were there for six months every single day all day and he actually did come through and was walking at the end of it.

motor bike
young
brain damage
daily for 6 mths
walked at end

J How do you feel about patients and their friends or relatives getting more involved in care in the ward?

N5 I think its a really good idea, I think it's going to be difficult to implement though.

good idea difficult to implement

J ..... difficult to implement?

N5 Ya, um ..... and I think unless the relative really wants to and is motivated to look after that patient or has an interest, I think it's going to be very difficult and I think so many relatives do have this idea that the nurses just take over and maybe they feel inadequate because they think we know what we are doing. So may be it's out fault as well, I think we have to change as well as the relatives.

relatives expect nurses to take over

- feel inadequate

- ? our fault

J In what way do we have to change?

N5 I think we have to be more receptive to the fact that relatives can do a lot of what we're doing and we have to make it a lot easier for them to take over our role and not just go in there and try and take over, but to stand back and let them do it and maybe talking to them about it and see how they feel.

nurses need to stand back & let lay people be involved

N5 Right. I want to look at the advantages and disadvantages of this type of care for patient's friends and relatives and perhaps we could begin by looking at the advantages or the benefits of getting patients and their family and friends more involved in care, and look at it from the patient's point of view. What do you see as being the advantage from the patient's point of view?

N5 Um ..... Well again, it's very difficult to say because I think some patients would ..... obviously would like their wives or husbands or family to look after them and I think others probably wouldn't want their nearest and dearest near them. So I think it's ..... you have to find out what the patient needs, but really ..... I don't know, I suppose cause I haven't really thought about it.

assess patients desire for involvement

not really thought about it

J Right. Should we begin by looking at the disadvantages for the patient's point of view? Can you think of disadvantages of getting the patient or family and friends more involved in care?

N5 Um .... well only that I think that patients probably do have, rightly or wrongly, confidence in the nursing and medical staff and so they take it for granted that we know what we're doing and therefore do tend to put a lot of trust in us which they might not put into the relatives.

take for granted that professionals know what to do

not trust relatives to care

J Right.

N5 And also it is a lot easier, like there's been so many times when we're working and they so oh I've tried, you tell them nurse, you know and it's true you sort of say you've got to do it, you know, or you do this and they will think, oh she's OK she's a nurse, whereas with a wife or relative they tend to tell them to stop nagging or whatever. So I don't know, but I do generally think that relatives should have more say in patient care.

patients less likely to do what relative says

J And thinking about the disadvantages, can you see any disadvantages on the part of the friends or relatives getting involved from their point of view?

N5 Yes, I would hate that a relative would feel guilty for not taking part and I think that would be very difficult to implement. Obviously I mean a lot of people work or have other lives or cleaning or feeding an ill patient just isn't for them, you know. I mean a lot of my friends wouldn't particularly relish the thought of having to look after an ill person.

feel guilty not participating

other commitments not for them (cleaning & feeding)

J Can you think of any other disadvantages for friends and relatives?

N5 Um ..... No not ..... no just the patient would become ..... might become too dependent on that relative.

too dependent on relative

J Too dependent?

N5 Um ..... well just might expect them to be around to look after them all the time and they might not feel able to take that on.

burden - expected to take on too much

J Can you think of any disadvantages from the health professionals point of view, doctors and nurses?

N5 Yes, I think we'd have to change our whole way of thinking and of working to revolve around the patients and their relatives rather than around our ward work, which although I think would be a good idea I think it would be very difficult to have ..... I mean at the moment I don't like the way we wash everyone in the morning, we do certain things at certain times, but it is done so that the ward runs smoothly and I'm not sure how it would work if we had relatives and people coming in at odd times during the day to look after the patients, but I think it would be a very good idea, and that's what happened on the chemotherapy and radiotherapy unit, but its was so small that it didn't matter and there wasn't so much general busyness going on so you could implement it, whereas here with doctors rounds and the phone going and drug rounds, everything just takes so much longer to organise that I don't know if it would be possible of not.

change way of thinking and working

wash in morning routine care (don't like but? efficient)

Disrupt ward routine - smooth running

Difficult - big/busy - hard to organise

J Any other disadvantages from the health professionals point of view?

N5 Only that ..... yes also I think the relatives would then demand ..... all the patients would begin to demand to know a bit more what was going on then perhaps they do now, so the medical and nursing staff would have to be prepared to let them in on more information than perhaps they already get, which is a good idea again but takes up a lot of time.

Patients demand more - time consuming

J Right. Can you talk a little bit more about that. Your feelings about that, giving information and how you feel about it?

N5 I think ..... I think on the whole both doctors and nurses are terrible at giving out information to relatives and patients, and I think that I would like to see the nursing staff being able to give a lot more information and being able to talk through it with relatives rather than the doctors coming round on ward rounds and in five minutes telling so an so what's wrong with them or what they're going to do. But I also think we're kept in the dark until the last minute and then we're expected, you know, to answer the relative's questions and we don't know what's going on.

poor at information giving
- should be better
Doctor gives information on ward round
Nurses in the dark - unable to answer questions
Need to be more aware to talk to relatives

J Why don't I know what's going on?

N5 'Cause quite often ..... well we go on the ward rounds ands we don't necessarily ..... I think half of them should come back and go through all the patients with us every day which certainly doesn't happen, which isn't their fault 'cause they are very busy. But I just think there is a lack of communication between nursing and medical staff. Unless you're personally on the ward rounds you do tend to feel a bit left out on what's going on.

Need daily handover with doctors
Poor communication on ward
- nurses|doctors
- nurses|nurses

J Any other disadvantages for health professionals?

N5 Not that I can think of.

J Let's try and look at the advantages then. Can you see any advantages for the patients?

N5 Um ..... some patients yes. I think ..... I think ..... if you have loving families or relatives that are willing to get involved in your care, I think it would aid their recovery, and also I think if we're trying to get them home then they know and the spouse or relative knows how much that patient is able to do rather than us saying yes, he is able to

aid recovery

do this and then getting home and there he is not able to do any of those, it's just that we've been standing over him and he's done it. So I think they would be more prepared then for having the relatives back in the community, which perhaps they're not at the moment.

Know what capable of after discharge

Better prepared to have patient back at home

J You began by saying some patients .....

N5 Because of ..... I mean I think you'd have to look at each case as an individual. I mean we just have so many different types of patinas on a ward, I don't think you can really generalise. I think what works for one patient might not necessarily work for another patient.

Can't generalise

J Do you see any other advantages for patients in particular?>

N5 um ..... no ..... I have to think about it.

J You can always come back if you get any other ideas. What advantages for the friends and relatives involved?

N5 I think again on certain levels, I think they'd be really happy to get involved and would feel that they were looking after that patient and doing ..... they obviously love that patients and so they're doing what they can for them rather than just standing by leaving everybody else do everything. But again, it's such an individual problem.

Certain levels happy to be involved

Feel doing something useful

J You'd have to look at every individual and their families and find out what they want.

Individualise

J Any other advantages that you could identify?

N5 No.

J Right. Let's look at it from the health professional's point of view. What can you see as being the benefits or advantages for the health professionals of this type of care?

N5 Um ..... Well it probably ..... if it worked obviously it does save time for the nurses if we're not spending a whole day washing patients and doing things that other people are quite capable of doing. It does leave us with more time to sort out other problems, sit down and talk to people longer and find out where they need the help and not just rushing in and doing it all. But I think it has advantages for all of us.

Save time
Frees time to talk to people & find out what they want

J Right. Can you think of any other advantages?

N5 I think ..... well it just brings the whole ..... them closer together so that we know what we're tackling, we'd have more communication with the relatives and I think we'd be able to prepare them more for going home and we'd see how they coped on the ward rather than just assuming that someone's going to cope when they go home, with not actual having put it into practice.

Better communication with relatives

Patients prepared better for discharge

J Any other thoughts about advantages or benefits for the health professionals?

N5 Not that I can think of.

J Right. As you know I intend to feedback my findings to the multidisciplinary team with a vu to making changes in practice on the ward and then monitoring these changes. Do you think that this ward is actually ready for change?

N5 I think it needs to change.

Needs to change

J Needs to change?

N5 Ya, desperately. Um ..... ya I think it is ready for change.

J In what way does it need to change?

N5 I think a lot of things on this ward have just been done over the years and perhaps not much thought has gone into it and I think we all needs to be a bit more enthusiastic about what we're doing and where we're going rather than just carrying on in the old way.

Do things without thinking
Always done in old way

J Do you feel it's ready for change?

N5 That's difficult to say because until you've got staff nurses and sisters or whatever who are happy working here and willing to change then no, and at the moment we've got so many people swapping and changing and not staying her very long that it makes it very difficult, but I definitely think it needs it.

Need more enthusiasm
Needs new direction
Not ready to change

J What difficulties do you think we might encounter making these changes?

- Staff turnover
- not happy
- not willing to change

N5 Um ..... I think it's just we all have to work to accept that we do have to work harder and be a bit more enthusiastic and get some results and I think we have worked closer together as a team which perhaps doesn't go on at the moment, I don't know.

Need to work harder
Be more enthusiastic
Work closer together

J Any other difficulties that you think you might encounter, not necessarily just with this staff?

N5 I think we might encounter difficulties with the relatives and the patients trying to explain what we're trying to do, and I think lot of relatives could get the impression that we're just short of staff and we want them to come in and wash the patient, which isn't the idea, so I mean I think it is going to be quite a difficult task, but hopefully worthwhile in the long run.

Hard to explain to patients + relatives
May think off-loading

J Any other difficulties?

N5 Um ..... well again we'll all have to get out of our old ways and rearrange our work and work around the patients and

Change old ways

the relatives and be enthusiastic about it which id all very easy to say but everyone's very bad at changing, myself included.

Hard to change

J Why?

N5 Well I don't know.

J Any other thoughts?

N5 No, just I mean I think it would have to be taken one step at a time slowly.

One step at a time

J One step at a time?

N5 Well new ..... you know implementing one thing at a time and try ..... I mean I don't think you could change this ward drastically overnight.

J How long do you think that change might take?

N5 God knows ..... 8 years..... (laughs) I don't know.

8 years

J Six months ..... a year ..... longer than a year?

N5 Well I hope ..... I mean I would hope ..... would like to see it in 3 to 6 months, hopefully but I mean I don't know, I don't have much experience about wards changing so I don't really know.

3-6 months

J What changes would you like to see made which involve patients and their family and friends in care in hospital?

N5 Well ..... as I said earlier I would like relatives to be given far more information about their illnesses, I also do think that a lot of patients ..... even patients that are independent ..... we take away their independence, we take away that rug, we take away all responsibility from them which I think is dreadful, I think they should be quite capable of

More information

Give more independence to patients

looking after things like that for themselves if they're independent enough. And I also think ..... relatives ..... we should communicate far better with the relatives, but also it's a lack of time ..... there's a lot of times when I would like to sit down and talk to relatives but I just don;'t have the time, 'cause you have to be prepared to sit down for an hour and let them explain what the problems are and you just don't have time to do it so .....

Talk more to relatives

Lack of time to talk to relatives

J You mention about the drugs, and patients being more responsible for drugs ..... is that a change you'd want to see implemented?

N5 I would like to see patients who are capable of taking ..... who are on medications at home, taking their own medications in hospital and understanding what they're for and that sort of thing.

self medication

J Any other changes that you feel we should make?

N5 Um ..... there are probably hundreds but ..... well I would like to see Primary Nursing care.

Primary Nursing

J Primary Nursing in what sense?

N. That we all have patients that we are actually involved with from the beginning to the end of their care and so a staff nurse or student or whatever would be in change of looking after that patient right the way through and a doctor would have to come back to the person responsible and everyone and in the multidisciplinary team would come back to that person responsible for looking after the patient. And therefore I could see that the communication then would be a lot better.

Continuity of care

Improve multidisciplinary Communication

J Hoe do you see patient participation fitting with Primary Nursing?

N5 Because I think if you're looking after that patient from the beginning to end you know yourself what that persons needs are and you are more likely to find out from the patient that their needs are instead of you know, 10 different nurses looking after that patient and each one maybe finding out different problems am but because of lack of communication they don't ..... it doesn't always get passed on.

Find out patient needs more

j How do you think people would feel on this ward about Primary Nursing?

N5 Most people are quite enthusiastic but ..... well ..... the sister won't actually implement it but if we did all the background work she would probably implement it. If we found out that it could work on this sort of ward then I think she'd give it a go. I don't know.

Enthusiastic
Sister won't implement unless background work done

J Can you think of any particular patients on the ward at the moment who would benefit from being more involved in care or their relatives being more involved in care.

N5 Um ..... X maybe .....but I don't know that's quite a difficult .....

J Can you tell me what's wrong with X?

N5 She's got liver sclerosis due to the fact that she's been steadily drinking more over the past six months due tot the break up of her marriage, etc. She is now ..... she is very jaundiced, very enlarged liver and probably ..... well could be terminal, they don't really know. But she's got three young children, the youngest being 15 and a sister, and I mean a lot of relatives so .....

Alcoholic liver disease - terminal

J Are they participating in the care at the moment?

N5 Um ..... when they're there which is a lot ..... I mean things like feeding her and encouraging her to drink and even

Feeding
Drinking

putting her on and off a commode so ya ..... to that extent but I mean none of us have actually tried to encourage them to do any more, I don't know if they would say it was too much which is always a problem.

Toileting
Nueses not encouraging them to do more
? too much

J Can you think of any other patients on the ward that would benefit from this type of care?

N5 Um ..... well X I think definitely but then his wife is involved in his care quite a lot and she has looked after him for quite a few years at home

wife cares for him at home

J What's wrong with X?

N5 He's had a left cerebrovascular accident in the past and ..... which has left him with quite a strong right sided weakness and also difficulty swallowing.

C.V.A.

J What aspects of his care is his wife involved in?

N5 Well she will ..... well at home she looks after him personally, here I mean she feeds him, she helps us when we're washing him and just generally.

Feeds him
Washes him

J Do you think she'd like to be more involved in hospital?

N5 I don't know ..... you see again I mean for her maybe it's quite a nice break so no, I would be loath to actually say to her, you know would you like to come in and wash him because she's doing it seven days a week at home, so O don't know, it's very difficult.

? Needs a break
– therefore don't want to suggest participation

J Any other particular patients who you think would benefit from this type of care? Either themselves getting more involved or their friends and relatives getting more involved?

N5 Um ..... no I can't think of anyone else on the ward who has got friends or relatives who could come in.

No friends / relatives

J And patients who themselves could get more involved in their own care?

N5 Well yes a lot.

J In what way could they become more involved?

N5 A lot of them, well in fact the majority of them are very happy just to sit back and let us do everything for them.

People happy to sit back & let us do for them

J Why?

N5 Well I' sure a lot of them are fairly elderly and tired with life and don't really want to be bothered, don't feel that wall and when you don't feel that well you just want to lie back and let everything be done for you so ..... and it's quite difficult again when you're very busy to sit down and try and motivate a patient so I don't think on a ward there is much motivation as far as I can see.

Eldeely
Tired with life
Can't be bothered
Feel unwell
No time to Motivate

J Can you think of any patients on the ward that would certainly not benefit from this type of care?

N5 Um ..... ya well Mr Y is terminally ill with acute pancreatitis and he's got to the stage where he hasn't really got family and friends to look after him and we have tried to get him involved but it really didn't work out and I think really he just needs to be left and I'm quite happy to do anything for him. Well ..... Z?

Pancreatitis
- terminal
- no family

J What's wrong with Z?

N5 She's really a social admission - old age and she'd in here till her last days really.

Social admission

J And how would she benefit from this type of care?

N5 I don't really think she's in any fit state to look after herself, she doesn't have any relatives and I think we'd be taking on a mammoth task in trying to get her to do any thing.

No relatives
Can't look after herself

J Any other patients on the ward?

N5 Well the others are all quire self caring.

J You say self caring, what are they doing for themselves?

N5 Well in the fact that they get up and they'll wash themselves and they'll eat without having to make them eat.

Other patients self caring

J What sort of things are they not doing that perhaps they could do or not do that you feel maybe they should do?

N5 Um ..... well things like fluid balance charts they could ..... like ..... and we do get patients that fill them in but I think they should fill them in if they are able to. Drugs ..... I think they should be taking care of their own drugs especially if they're then going to go home on these drugs, I think they should start taking them on their own in hospital. And maybe ..... at the moment we don't really sit down with the patient and say let's plan your care or what you feel you want from us which is perhaps we should do ..... well we should do.

Not doing
- fluid balance charts
- self administration
- involve patient in plan of care

J Right. Have you any experience yourself of being in hospital or having a friend or relative admitted to hospital?

N5 No

J There's no experience there you can think of?

N5 No

J Right, well in that case can you think of anything else that you might like to say that we haven't already addressed.

N5 No. Not that I can think of. None

(At this stage something wad dropped and then .....)

N5 I don't feel that I know the patients relatives and their background very well because I don't have time to sit down and talk to them for an hour and find out what all their problems are but I think if Primary Nursing care or like where I was looked after a certain amount of patients from the beginning to the end I would get more involved and be more interested but when I know OK I'm that side today and I'm looking after someone else tomorrow there's a limit to you know how many hours you can spend with each one of them. Don't know patients Primary Nursing would help to get to know them No time to talk to patients, the way the ward is organised. Moved around ward too much

Stage 2 Example: Summary of issues/points from transcript of one nurse in relation to each question asked at initial interview

N5 Initial Interview 18 pages 23/9/88

Qualified	2 years	
Trained	Royal Berkshire	
Experience	6 months	skiing
	6 months	agency
	4 months	voluntary nursing (Calcutta)
	3 months	travel
	6 months	1st staff nurse post (current job)

Previous experience of LPC

Chemotherapy/Radiotherapy (washing/feeding)

Odd cases - motor bike accident, brain damaged

General Feelings to LPC

Good idea

Difficult to implement — public expect nurses to take over (feel inadequate)

nurses need to stand back (allow/talk about involvement)

Not really thought about it before

Don't like way ward is routinely organised

Nurses should be able to talk to patients and relatives more
Not many patients have friends or relatives who come in to visit
Patients tend to sit back and let us "do" for them
Patients are elderly, tired with life, can't be bothered, feel unwell - no time to motivate them
Need Primary Nursing to implement LPC

Advantages from patients' perspective
Aids recovery

Advantages from relatives' perspective
Better prepared for patient's discharge
Understand what letting themselves in for after discharge
Feel doing something useful
Happy to join in at certain levels

Advantages from professionals' perspective
Save time
Frees time to talk to patients and relatives and find out what they want
Better communication with relatives
Patients prepared better for discharge

Disadvantages from patient's perspective
May not trust the relatives to care
Take it for granted the professionals know what they are doing
Patients less likely to do what relative tells them
Might become too dependent on relative

Disadvantages from relative's perspective
May feel guilty for not taking part
Other commitments - work, own lives
May not be for them (cleaning, feeding)
Burden - patient might expect them to be around all the time
May think we are off loading work
May need a break if caring already at home

Disadvantages from professional's perspective
Need to change way of thinking and working
Disrupts smooth running of ward

Difficult to implement (too big a task, too busy, hard to organise)
Patients would demand more - too time consuming
Lack of time to talk to relatives

Ward ready for change

Needs to change - too routine oriented, old fashioned, lacks enthusiasm and direction
Not ready - high staff turnover, staff not happy, staff not willing to change

State of the ward

Ward routine oriented - wash in mornings, do things at certain times
Nurses poor at information giving - doctors do this on ward rounds
- nurses in the dark (unable to answer questions)
Poor communication on the ward - messages not passed on inter and intra professionally
Many different types of patient on the ward - can't generalise
Old fashioned - do things in old way
Need new direction and more enthusiasm
Staff turnover high, lack of willingness to change, staff not happy on ward
Lack of teamwork
Charge nurse won't implement Primary Nursing unless background work done by others
Staff nurses enthusiastic to implement Primary Nursing
Not asking lay people to participate in care - worried won't want to, ?too much
Many patients just sit back and let us "do" for them
Patients are not involved in care planning
Patients who are on "self care" eat and wash only
No time to talk to patients at moment
Don't know patients in much depth
Staff are moved around the ward too much

Difficulties changing practice

Need to work harder, be more enthusiastic, work closer as a team
Difficult to explain to lay people what trying to do (think off loading jobs)
Need to change old ways and focus on individual patients (people bad at changing)
Lack of time to talk to relatives and patients (hard to motivate them)

Suggestions for change

Assess patients' desire for involvement
Nurses should be more aware of what is going on so that they can talk to relatives
Need daily handover with medical staff
Need to individualise - can't generalise care

Need to work harder, be more enthusiastic and work closer as a team
Need to explain to patients and relatives that not off loading responsibilities
Need to work round patients and change old ways
Take one step at a time
Give more information to patients and talk more to relatives
Encourage more independence in patients
Introduce self medication, self monitoring of fluid balance charts
Introduce Primary Nursing - continuity of care
- improve multidisciplinary team communication
- assess patients' needs better
Involve in care planning

Particular patients who might benefit
Alcoholic liver disease patients (terminally ill): regular visitors (feed, toilet, give fluids)
Cerebrovascular accident patients (relatives could help feed and wash)

Particular patients who might not benefit
Patients with pancreatitis (terminally ill): no family
Social admissions - not capable of independence, no family

Personal experience of LPC
None

Stage 3 Example: Amalgamated issues/points raised by the different subgroups (nurses, medics, paramedics, joint group) for the question asked at initial interview concerning the disadvantages of lay participation in care from the patient's perspective

NB. Original shows which individual raised which issue (large matrix)

Disadvantages from patient's perspective

Issues/Points Raised	N	M	P	J
Nothing	1	3	1	5
Seen as intrusion-overpowered, fussing, not want attention	1	5	3	9
Worried about taking responsibility for illness/scared	3	2	1	6
See patients role as passive-professional paid to give care	3	3	2	8

Stage 3 Example continued

NB. Original shows which individual raised which issue (large matrix)

Disadvantages from patient's perspective

Issues/Points Raised	N	M	P	J
Don't see relevance-block involvement	4	1		5
Less contact with nursing staff		1		1
May not be motivated for involvement/prevention		3	4	7
Don't get on with relative	2	3	4	9
Not see care as good as professional care	6	3	4	13
Relatives too caring - loose independence	3	1	5	9
Some may feel left out if every one else has visitors	1	2		3
May not like to inflict self on others	2	1	1	4
Too much information can put off patient		1		1
May not want to hear prognosis		2	1	3
May not be able to decide what information important		1	1	2
May be afraid to ask questions (too anxious)		2	1	3
Don't understand treatments and condition		2	1	3
Not intelligent enough to understand	1	2		3
Misunderstand-not trained sufficiently		2		2
May do harm	3	3	2	8
May not get on with family	2	2	1	5
May not like closeness with family-too personal	7	4	4	15
May welcome break from family-enjoy hospital		2	1	3
May become neurotic, hypochondriac, anxious	1	2		3
May not like independence being taken away		2	1	3
May be discharged without commitment in community		2		2
May change relationship with relative-strain	1	1	2	4
Relatives may be in conflict with medicine		1		1
May not be capable of involvement (not cope)	2	1	3	6
Conflict may arise if patient disagrees with relative		1	4	5
May become fed up with illness		1		1
May be too sick	3	1	1	5
May forget to do care (confused, memory loss)	2	1		3
In hospital got other things to think about			1	1

Stage 3 Example continued

NB. Original shows which individual raised which issue (large matrix)

Disadvantages from patient's perspective

Issues/Points Raised	N	M	P	J
May upset patient because know too much			3	3
Insufficient time to adjust to illness			1	1
May have no relations	3		2	5
May feel confidentiality at risk	6		4	10
Lead to misunderstandings if family give care wrongly			1	1
May want to pretend there is no problem			1	1
May feel given too much to do (burden)	8		1	9
Feel not enough time or space to be on own	1		2	3
May prefer someone more distant-to be honest			1	1
Feel failure if can't manage-reluctant to admit	2			2
Patient less likely to do what relative tells them	1			1
May feel neglected if self caring	1			1
May not want to be seen when ill	1			1
Nurse may involve family without consultation	1			1

Example: Quote card for one of the nurses' initial interview

N5 Initial Interview Quotes

Page	Type of Quote
5	Recognises need to change approach to work focusing on patients not routines
6	Nurses kept in the dark - don't know what to tell patients
9	Ward in a rut
10	Need to work harder and be more enthusiastic for change
12	Tend to take away patients independence in hospital
15	Some relatives need respite care whilst patient is in hospital
15/16	Patients happy to sit back and be passive
18	Need to introduce Primary Nursing to implement LPC

Stage 4 Example: Issues/points grouped into themes for the question asked at initial interview concerning the disadvantages of lay participation in care from the patient's perspective

DISADVANTAGE - PATIENT

M=Medical (14), P=Paramedical (13), N=Nursing (18), J=Joint (45)

Invasion of Privacy/Independence	**M %**	**P %**	**N %**	**J %**
May not like closeness with family - too personal	**29**	**31**	**39**	**33**
Seen as an intrusion - not want the attention	**36**	23	6	20
May feel confidentiality at risk		**31**	**33**	22
May not like independence being taken away	14	8		7
Not enough time/space to be on own		15	6	7
May not want to be seen when ill			6	2
Nurse may involve family without consultation			6	2
Lay care not as good as professional care	**M %**	**P %**	**N %**	**J %**
May not see care as good as professional care	**29**	**31**	**39**	**33**
Relatives too caring - may loose independence	7	**38**	17	20
Fear do harm	21	15	17	18
May not be capable of involvement	7	23	11	13
May forget to do care - confused/memory loss	7		11	7
Misunderstand -not trained sufficiently	14			4
May prefer someone more distant - easier to be honest		8		2
May be neglected if self caring			6	2
Intrusion on own/others lives	**M %**	**P %**	**N %**	**J %**
Given too much to do - burden		8	**44**	20
May not like to inflict self on others	7	8	11	9
Family conflict	**M %**	**P %**	**N %**	**J %**
May not get on with family	21	**31**	11	20
May welcome break from family - enjoy hospital	14	8		7
Conflict - if patient disagrees with relative e.g. re. prognosis	7	**31**		11
May change relationship with relative - strain	7	15	6	9
May become fed up with illness	7			2
Misunderstandings if family give care wrongly		8		2
Participation not part of patient role	**M %**	**P %**	**N %**	**J %**
Patient role is passive-professional paid to do job	21	15	17	18
May not be motivated towards involvement /prevention	21	**31**		16
Don't see relevance - block involvement/not want it	7		22	11

Stage 4 Example continued

DISADVANTAGE - PATIENT

M=Medical (14), P=Paramedical (13), N=Nursing (18), J=Joint (45)

No Disadvantages for Patient	**21**	**8**	**6**	**11**
Participation may cause more anxiety	**M %**	**P %**	**N %**	**J %**
May not want to hear prognosis	14	8		7
May upset patient because know too much		23		7
Worried about taking responsibility for illness-scared	14	8	17	13
In hospital got other things to think about		8		2
Want to pretend there is no problem		8		2
May become hypochondriac/neurotic/anxious	14		6	7
Feel failure if can't manage - reluctant to admit			11	4
Can put patient off -too much information	7			2
Unable to participate	**M %**	**P %**	**N %**	**J %**
May be too sick	7	8	17	11
May have no relations		2	3	5
May be afraid to ask questions -too anxious	14	1		3
Insufficient time to adjust to illness		1		1
Not capable of participation	**M %**	**P %**	**N %**	**J %**
Don't understand treatment/condition	14	8		7
Not intelligent enough to understand	14		6	7
May not be able to decide what information important	7	8		4
Miscellaneous	**M %**	**P %**	**N %**	**J %**
May feel left out if everyone has visitors	14		6	7
Relatives may be in conflict with medicine	7			2
Professional loss of control	**M %**	**P %**	**N %**	**J %**
May be discharged into community without commitment	14			4
Loss of contact with nursing staff	7			2

APPENDIX XVIII

SUMMARY OF FINDINGS: MODIFIED PATIENT AND FAMILY INVOLVEMENT IN NURSING CARE SCALE BROOKING (1986)

The Patient and Family Participation in Nursing Care Scale was used to assess the health professionals' attitudes towards lay participation in hospital care. The triangulation of this data with other data (interview, participant observation) will be explored in the discussion chapter. The limitations of using attitude scales to measure complex phenomena will be demonstrated. Data from the multidisciplinary team in this study was compared with data from the professional group of nurses in Brooking (1986)'s study. This was done to ascertain whether the group of professionals under study were any different to the group of professionals that were chosen more randomly by Brooking in 1986. By providing this contextual information, it was thought that the reader might be in a better position to judge the relevance of this study to his or her own area of practice. Data was also compared within the multidisciplinary team to ascertain whether any particular subgroup (qualified nurses, learner nurses, medical staff, paramedical staff) held different attitudes towards this concept which might effect the overall results of the study.

The Patient and Family Participation in Nursing Care Scale consists of several subscales. The findings from each subscale will be presented in turn.

Subscale 1: "Attitudes Towards Patient and Family Participation in Care"

This subscale was completed by 51 members of the multidisciplinary team (qualified nurses n=14; learner nurses n=17; medical staff n=11; paramedical staff n=9). Following the format used for Brooking's study, the 24 items were scored from 0-5, so that a high score indicated a positive attitude and a low score indicated a negative attitude towards the issues. As in Brooking's study, "No answer" scored 0, however in contrast to Brooking's study it was not possible to score 3 for any item as the "Don't know" category was removed. This was done in order to force participants to give an opinion as Brooking had identified a central tendency in the use of her scale. This therefore meant that the overall scores could not be directly compared between the multidisciplinary team in this study and the professional group in Brooking's earlier work. However it was possible to look at the difference in response between the groups for each individual item

to ascertain whether the group under study tended to hold more positive or more negative views. A point system was devised to do this which will be described in the next section.

Comparison of Multidisciplinary Team With Professional Group in Brooking (1986)'s Study for Subscale 1

Table 38 shows the number and percentages of nurses (qualified plus learners); non-nurses (medical plus paramedical) who responded to each category for each item; joint group (all multidisciplinary team members together) compared with the professional group of nurses (n=107) from Brooking's earlier study (Brooking, 1986). This was done to ascertain whether the multidisciplinary group in this study held overall more or less positive attitudes compared to the professional group (nurses) in Brooking's study. Scores could not be directly compared since the questionnaire had been modified by removal of the "don't know" category. However it was possible to award correspondingly positive and negative points in relation to whether for each item the joint group showed more positive attitudes or more negative attitudes compared to the nurses in Brooking's study. In this way trends could be explored rather than actual values compared. Points were awarded on the following basis:

Code	Points	% Difference between Joint and JB	
+/-a	+/- 1	<10%	
+/-b	+/- 2	11-20%	
+/-c	+/- 3	21-30%	+ indicates more positive compared to JB
+/-d	+/- 4	31-40%	- indicates less positive compared to JB

The last column of Table 38 indicates the total points (+ indicates more positive attitude; - indicates less positive attitude) awarded to the joint group compared to Brooking's nurses for each of the 24 items. Overall a total score of +63 indicated that the multidisciplinary team held more positive attitudes towards patients and their family and friends becoming involved in nursing care compared to the professional group of nurses in Brooking's earlier study (Brooking, 1986).

Table 38: Attitudes Towards Patient and Family Participation in Care Scale

Comparison of joint group (multidisciplinary team) with professional group (nurses) in Brooking (1986)'s study

Item No	Grp	(no answer)		(strongly disagree)		(disagree)		(don't know)		(agree)		(strongly agree)		Points
		No	%	No	%	No	%	No	%	No	%	No	%	
1*	JB	0	0	5	4.7 *a*	39	36.4 *a*	2	1.9	52	48.6 *a*	9	8.4 *a*	*4 x a+*
	Joint	3	5.9	6	11.7+	19	37.3+			23	45.1+	2	3.9+	=+4
	Nurses	1	3.2	4	12.9	14	45.2			1	3.5	1	3.2	
	Non-N	2	1	2		5	25			12	60	1	5	
2	JB	2	1.9	1	0.9 *a*	11	10.3 *a*	5	4.7	65	60.7 *a*	23	21.5 *b*	*3 x a+ 1 x b+*
	Joint	1	2	0	0 +	1	2 +			31	60.8+	18	35.3+	=+5
	Nurses		0	0		1	3.2			19	6.3	11	35.5	
	Non-N	1	5	0	0	0	0			12	60	7	35	
3	JB	0	0	1	0.9 *a*	12	11.2 *a*	0	0	48	44.9 *a*	46	43 *a*	*3 x a+ 1 x a-*
	Joint	1	2	0	0 +	4	7.8 +			26	51 +	20	39.2-	=+2
	Nurses	1	3.2			2	6.5			16	5.6	12	38.7	
	Non-N	0	0	0		2	10			10	50	8	4	
4	JB	0	0	2	1.9 *a*	15	14 *b*	7	6.5	59	55.1 *a*	24	22.4 *b*	*2 x a+ 2 x b+*
	Joint	0	0	0	0 +	0	0 +			32	62.7 +	19	37.3+	=+6
	Nurses	0	0	0	0	0	0			16	51.6	15	48.4	
	Non-N	0		0	0		0			16	80	4	20	
5	JB	0	0	0	0	1	0.9 *a*	4	3.7	60	56.1 *b*	42	39.3 *c*	*1 x a+ 1 x b-*
	Joint	0	0	0	0	0	0 +			20	39.2-	31	60.8+	*1 x c+*
	Nurses		0	0	0	0	0			11	35.5	20	64.5	=+2
	Non-N		0	0	0	0				9	45	11	55	
6	JB	0	0	35	32.7 *c*	51	47.7 *b*	8	7.5	11	10.3 *d*	2	1.9 *a*	*1 x a+ 1 x b+*
	Joint	1	2	4	7.8 +	19	37.3 +			23	45.1 +	4	7.8 +	*1 x c+*
	Nurses		0	1	3.2	1	32.3			17	54.8	3	9.7	*1 x d+*
	Non-N	1	5	3	15	9	45			6	30	1	5	=+10
7*	JB	0	0	57	53.3 *b*	46	43 *b*	0	0	2	1.9 *a*	2	1.9 *a*	*2 x a+ 1 x b+*
	Joint	0	0	37	72.6 +	14	27.5 -			0	0 +	0	0 +	*1 x b*
	Nurses	0	0	26	83.9	5	16.1			0	0	0	0	=+2
	Non-N	0	0	11	55	9	45			0	0	0	0	
8	JB	0	0	0	0 *a*	0	0	2	1.9	31	29 *a*	74	69.2 *b*	*1 x a+ 1 x a-*
	Joint	1	2	1	2 -	0	0			19	37.3 +	30	58.8-	*1 x b*
	Nurses	1	3.2	0	0	0	0			8	25.8	22	71	=-2
	Non-N	0	0	1	5	0	0			11	55	8	40	
9	JB	0	0	1	0.9 *a*	0	0	1	0.9	25	23.4 *c*	80	74.8 *c*	*1 x a- 1 x c+*
	Joint	0	0	1	2 -	0	0			23	45.1 +	27	52.9 -	*1 x c -*
	Nurses	0	0	0	0	0				10	32.3	21	67.7	=-1
	Non-N	0	0	1	5					13	65	6	30	
10	JB	0	0	3	2.8 *a*	12	11.2 *a*	2	1.9	71	66.4 *b*	19	17.8 *d*	*2 x a+ 1 x b-*
	Joint	0	0	0	0 +	2	3.9 +			24	47.1 -	25	49 +	*1 x d+*
	Nurses		0	0	0	0	0			8	25.8	23	74.2	=+4
	Non-N		0	0	0	2	1			16	80	2	10	
11	JB	0	0	0	0	7	6.5 *a*	6	5.6	57	53.3 *a*	37	34.6 *a*	*1 x a+ 2 x a-*
	Joint	0	0	0	0	5	9.8 -			25	49 -	21	41.2 +	=-1
	Nurses	0	0	0	0	3	9.7			15	48.4	13	41.9	
	N n-N	0		0		2	1			10	50	8	4	
12	JB	0	0	0	0	0	0	0	0	50	46.7 *a*	57	53.3 *a*	*1 x a+ 1 x a-*
	Joint	0	0	0	0	0	0			23	45.1 -	28	54.9+	=0
	Nurses	0								9	29	22	71	
	Non-N	0	0	0		0				14	7	6	30	
13*	JB	0	0	14	13.1 *a*	64	59.8 *a*	14	13.1	13	12.1 *a*	2	1.9 *a*	*2 x a+ 2 x a-*
	Joint	3	5.9	11	21.6+	29	56.9 -			8	15.7 -	0	0 +	=0
	Nurses	3	9.7	8	25.6	17	54.8			3	9.7	0	0	
	Non-N	0	0	3	15	12	60			5	25		0	
14*	JB	1	.9	3	2.8 *a*	34	31.8 *c*	9	8.4	55	51.4 *b*	5	4.7 *a*	*1 x a+ 1 x a-*
	Joint	1	2	0	0 -	28	54.9+			21	41.2+	1	2 +	*1 x b+*
	Nurses	1	3.2	0	0	16	51.6			13	4.9	1	3.2	*1 x c+*
	Non-N		0	0		12	60			8	4			=+5
15*	JB	0	0	36	33.6 *c*	59	55.1 *b*	2	1.9	5	4.7 *a*	5	4.7 *a*	*2 x a+ 1 x b-*
	Joint	1	2	29	56.9+	21	41.2 -			0	0 +	0	0 +	*1 x c+*
	Nurses			2	64.5	1	35.5							=+3
	N n N	1	5	9	45		50							
16*	JB	0	0	5	4.7 *a*	54	50.5 *b*	12	11.2	31	29 *a*	5	4.7 *a*	*3 x a+ 1 x b+*
	Joint	2	3.9	3	5.9 +	34	66.7 +			12	23.5+	0	0 +	=+5
	N rses	1	3.2	2	6.5	24	77.4			4	12.9			
	N n N	1	5	1	5		50			8	4			
17	JB	1	9	5	4.7 *a*	18	16.8 *a*	6	5.6	65	60.7 *a*	12	11.2 *c*	*2 x a+ 1 x a-*
	Joint	1	2	0	0 +	4	7.8 +			30	58.8 -	16	31.4 +	*1 x c+*
	Nurses	1	3.2			3	9.7			13	4.9	14	45.2	=+4
	N n N					1	5			17	8	2	1	

Table38: continued

18*	JB	0	0	10	9 3 *b*	55	51 4 *b*	8	7.5	29	27.1 *c*	5	4.7 *a*	*1 x a+ 2 x b+*
	Joint	1	2	13	25.5 +	34	46 7 +			3	5 9 +	0	0 +	*1 x c+*
	Nurses		0		5 5	18	5			2	6 5		0	+8
	Non-N	1	5	2		16	80			1	5	0		
19	JB	0	0	0	0	1	.9 *a*	3	2.8	57	53 3 *b*	46	43 *b*	*1 x a+ 1 x b+*
	J nt	0	0	0	0	0	0 +			21	41 2 -	30	58 8 +	*1 x b-*
	Nurses	0	0	0						10	32 3	21	67 7	=+1
	N n-N		0		0					11	55	9	45	
20	JB	0	0	0	0	0	0 *a*	0	0	34	31 8 *a*	73	68 2 *a*	*1 x a+ 2 x a-*
	Joint	0	0	0	0	1	2 -			14	27.5 -	36	70 6 +	=-1
	Nurses	0	0	0	0	0	0			7	22 6	24	77 4	
	N n-N	0	0		0	1	5			7	35	12	60	
21*	JB	0	0	10	9.3 *a*	52	48 6 *c*	11	10 3	25	23 4 *b*	9	8.4 *a*	*2 x a+ 1 x b+*
	Joint	1	2	6	1 .7 +	37	72 6 +			6	11 7 +	1	2 +	*1 x c+*
	Nurses	0	0	5	1 1	22	71			4	12 9	0		=+7
	Non-N	1	5	1	5	15	75			2	10	1	5	
22	JB	0	0	0	0	4	3.7 *a*	0	0	42	39.3 *a*	61	57 *a*	*3 x a-*
	Joint	1	2	0	0	2	3.9 -			20	39 2 -	28	54 9 -	=-3
	Nurses	0		0	0	2	6.5			10	32 3	19	6 3	
	Non-N	1	5	0	0	0	0			1	50	9	45	
23	JB	0	0	0	0	5	4.7 *a*	3	2.8	47	43 9 *a*	52	48 6 *a*	*2 x a+ 1 x a-*
	Joint	0	0	0	0	2	3.9 +			25	49 +	24	47 1 -	=+1
	Nurses	0	0		0	1	3 2			13	4 9	17	5 4 8	
	Non-N	0	0	0	0	1	5			12	60	7	35	
24*	JB	0	0	2	1 9 *a*	20	18.7 *a*	8	7 5	67	62.6 *a*	10	9.3 *a*	*3 x a+ 1 x a-*
	Joint	1	2	2	3 9 +	12	23 5 +			31	60.8 +	5	9 8 -	=+2
	Nurses	1	3 2	2	6 5	6	19 4			18	58 1	4	12 9	
	Non-N	0	0	0	0	6	3(			13	65	1	5	
Points					*13xa+ 3xa- 1xc+* =+13		*12xa+ 4xa- 4xb+ 1xc+* =+19				*7xa+ 6xa- 2xb+ 5xb- 3xc+ 1xd+* =+8		*9xa+ 4xa- 5xb+ 1xb- 3xc+ 1xc- 1xd+* =+23	*41xa+ 17xa- 11xb+ 6xb- 8xc+ 1xc- 2xd+* =+63

JB: Brooking's Professional Group (nurses n=107); Joint: This Study's Professional Group (multidisciplinary team n=51)
Nurses: Qualified Nurses (n=14) plus Learner Nurses (n=17); Non-Nurses: Medical Staff (n=11) plus Paramedical Staff (n=9).

*: Indicates items that require a respondent to disagree in order to show a positive attitude to lay participation in care

Code	Points	% Difference between Joint and JB	
+/-a	+/- 1	<10%	
+/-b	+/- 2	11-20%	
+/-c	+/- 3	21-30%	+ indicates more positive compared to JB
+/-d	+/- 4	31-40%	- indicates less positive compared to JB

Table 39 shows the items in rank order from the greatest change in positive attitude change to the greatest change in negative attitude for the multidisciplinary team compared to the nurses in Brooking's study. The overall points for each item is given plus an indication of which subscale each item originated from:

Subscale A: Patient and Planning Subscale
Subscale B Patient Implementation Subscale
Subscale C Relative Planning Subscale
Subscale D Relative Implementation Subscale

Looking at Table 39, findings show that where the multidisciplinary team was more positive, compared to Brooking's nurses, it tended to occur with items in the Patient Planning and Implementation Subscales (i.e. items 6, 18, 21, 4, 2, 14, 16). Where the multidisciplinary team showed more negative attitudes compared to Brooking's nurses, it tended to occur with items in the Relatives Planning and Implementation Subscales and Patient Implementation Subscale (i.e. items 22, 8, 9, 11, 20).

Table 39: Attitudes Towards Patient and Family Participation in Care Scale
Items in rank order from the greatest change in positive attitude change to the greatest change in negative attitude for the multidisciplinary team compared to the nurses in Brooking's study

Rank	Item	Pts	Sub
1	6. If patients are well enough they should be allowed to keep their own medicines in their lockers, and take them as prescribed.	+10	B
2	18. It will only lead to problems for the nurses if relatives are allowed to do too much for the patient	+8	D
3	21. Relatives must accept that nurses have the training and experience to assess the patients needs without interference from the family.	+7	C
4	4. When nurses are considering what is best for a particular patient, they should ask him what he prefers.	+6	A
5	2. When a patient is first admitted, the nurse should ask him which of his problems and needs he regards as most important.	+5	A
5	14. It is always the nurses responsibility to decide on the most suitable time to renew the patient's bandage	+5	A
5	16. If a patient has a skin disease, the nurse should apply the ointment to ensure that it is rubbed in properly	+5	B
8	1. The essence of nursing is doing things for people to enable them to rest and relax in hospital	+4	B
8	10. Patients who are well enough should be allowed to write their own charts of how much fluid they are drinking each day.	+4	B
8	17. As far as possible, patients should be allowed to decide for themselves when they want to wash and bath.	+4	A
11	15. Relatives must accept that they are not entitled to do anything for the patient while he is the responsibility of the hospital.	+3	D
12	3. Relatives have a right to know what is being done to their "nearest and dearest" by the nursing staff.	+2	D
12	5. Information from a spouse about the patient's normal life style helps nurses to assess what care will be required.	+2	C
12	7. Patients must accept that whilst in hospital they have no right to question nurses' decisions about what needs to be done for them.	+2	A
12	24. Most patients are happy to hand over to the nurses complete responsibility for deciding what care they require.	+2	A
16	19. If a patient is going to need care at home, the nurses should teach his wife how to look after him while he is still in hospital.	+1	D
16	23. In planning a course of rehabilitation after a stroke, the nearest relatives should be invited to contribute their ideas	+1	C
18	12. Patients are entitled to do things for themselves as long as they feel well enough, and provided it is medically safe.	0	B
18	13. It is up to the nurses to assess how often patients need to wash their hair whilst in hospital.	0	A
20	9. Even if it would be quicker for a nurse to dress an elderly lady, she should try to encourage the old lady to do it herself.	-1	B
20	11. Before an operation the implications and risks of surgery should be discussed with the patient's nearest relative.	-1	C
20	20. When a child is in hospital his mother should be encouraged to wash and feed him, provided this is medically safe.	-1	D
23	8. Nurses should encourage patients to be as independent as possible.	-2	B
24	22. It is good for both patients and nurses if relatives can help with simple tasks like giving the patient a cup of tea.	-3	D

Pts: Points
Sub: Subscale A Patient Planning Subscale B Patient Implementation
Subscale C Relative Planning Subscale D Relative Implementation

Comparison of Results Between Subgroups in Multidisciplinary Team for Subscale 1

An analysis of variance between the subgroups (qualified nurses n=14; learner nurses n=17; medical staff n=11; paramedical staff n=9) in the multidisciplinary team was measured using the Kruskal Wallis test.

Table 40 shows the mean ranks, Kruskal Wallis test statistic, and p-values that have been corrected for ties.

From this it can be seen that there was no significant differences between the subgroups of the multidisciplinary team except for the following isolated items.

Item 9 Even if it would be quicker for a nurse to dress an elderly lady, she should try to do it herself.

Examination of the cross tabulation tables reveals that the learner nurses "strongly disagreed" whereas the medical staff "agreed" with this item.

Item 10 Patients who are well enough should be allowed to write up their charts of how much fluid they are drinking each day.

Examination of the cross tabulation tables reveals that the qualified nurses "strongly disagreed" whereas the medical and paramedical staff "agreed" with this item.

Item 12 Patients are entitled to do things for themselves as long as they feel well enough, and provided it is medically safe.

Examination of the cross tabulation tables reveals that the qualified nurses "strongly disagreed" whereas the medical and paramedical staff "agreed" with this item.

Table 40: Attitudes Towards Patient and Family Participation in Care Scale
Mean ranks, Kruskal Wallis test statistic, and p-values that have been corrected for ties.

Item	Mean Ranks	Mean Ranks	Mean Ranks	Mean Ranks	Kruskal Wallis	p-value
	Qualified Nurse	Learner Nurse	Medical Staff	Paramedical Staff		
1	28.62	27.03	17.28	21.00	5.6011	0.1327
2	19.36	29.97	24.35	27.89	6.1358	0.1052
3	25.19	26.09	23.14	27.72	0.6688	0.8805
4	29.25	28.50	18.82	25.00	5.3566	0.1475
5	25.07	28.50	26.73	21.83	1.7735	0.6207
6	29.43	27.71	16.85	24.83	5.8387	0.1197
7	27.54	30.00	23.73	18.83	6.2388	0.1006
8	27.96	29.74	19.00	21.89	6.2311	0.1009
9	27.29	32.12	14.18	26.89	13.1122	0.0044
10	30.25	34.68	15.55	15.78	21.3697	0.0001
11	26.79	25.71	23.64	28.22	0.6467	0.8857
12	30.21	30.00	21.27	17.67	8.4732	0.0372
13	24.92	28.09	18.09	25.39	4.4638	0.2155
14	23.46	25.78	27.59	25.61	0.6739	0.8793
15	28.86	25.71	26.00	19.33	3.2394	0.3562
16	29.15	26.53	20.30	21.33	4.5573	0.2072
17	23.96	32.03	22.14	19.50	7.5442	0.0564
18	27.21	28.00	23.35	20.50	2.9489	0.3996
19	27.39	29.00	22.59	22.33	2.6704	0.4453
20	26.36	29.09	21.45	25.17	2.8644	0.4130
21	27.54	26.00	23.50	23.61	1.0690	0.7846
22	24.64	28.03	26.90	20.50	2.2499	0.5222

Table 40: continued

Item	Mean Ranks	Mean Ranks	Mean Ranks	Mean Ranks	Kruskal Wallis	p-value
23	29.00	27.18	22.68	23.17	1.9937	0.5737
24	27.04	23.09	23.27	30.56	2.6093	0.4559

Subscale 2: "Care Activities in Hospital"
This subscale was completed by 51 members of the multidisciplinary team (qualified nurses n=14; learner nurses n=17; medical staff n=11; paramedical staff n=9). In this scale 20 common nursing procedures were listed. Respondents were asked to indicate by ticking boxes whether they considered patients and/or relatives would be able to carry out each of the procedures.

Table 41 shows the number and percentages of nurses (qualified plus learners); non-nurses (medical plus paramedical) who responded to each category for each item; joint group (all multidisciplinary team members together) compared with the nurses (n=107) from Brooking's earlier study (Brooking, 1986). As in Brooking's study, a tick was seen as displaying a positive attitude towards lay participation in care.

Table 41: Care Activities in Hospital Scale
Comparison of joint group (multidisciplinary team) with professional group (nurses) in Brooking (1986)'s study

Could be done by patient:					**Could be done by relative:**				
Item	**Group**	**Ticks**	**%**	**Diff**	**Item**	**Group**	**Ticks**	**%**	**Diff**
1	JB	90	84.1		1	JB	31	29	
	Joint	49	96.1	+12		Joint	34	66.7	+37.7
	Nurses	31	100			Nurses	21	67.7	
	Non N	18	90			Non N	13	65	
2	JB	92	86		2	JB	46	43	
	Joint	50	98	+12		Joint	39	76.5	+33.5
	Nurses	30	96.8			Nurses	25	80.6	
	Non N	20	100			Non N	14	70	
3	JB	104	97.2		3	JB	86	80.4	
	Joint	47	92.2	-5		Joint	45	88.2	+7.8
	Nurses	31	100			Nurses	28	90.3	
	Non N	16	80			Non N	17	85	
4	JB	99	92.5		4	JB	68	63.6	
	Joint	45	88.2	-4.3		Joint	35	68.6	+5
	Nurses	28	90.3			Nurses	23	74.2	
	Non N	17	85			Non N	12	60	
5	JB	34	31.8		5	JB	38	35.5	
	Joint	29	56.9	+25.1		Joint	38	74.5	39
	Nurses	22	71			Nurses	20	64.5	
	Non N	7	35			Non N	18	90	
6	JB	7	6.5		6	JB	8	7.5	
	Joint	16	31.4	+24.9		Joint	17	33.3	25.8
	Nurses	10	32.3			Nurses	11	35.5	
	Non N	6	30			Non N	6	30	
7	JB	59	55.1		7	JB	102	95.3	
	Joint	30	58	+2.9		Joint	51	100	+4.7
	Nurses	21	67.7			Nurses	31	100	
	Non N	9	45			Non N	20	100	

Table 41: continued

8	JB	25	80.6		8	JB	31	100	
	Joint	43	84.3	+3.7		Joint	51	100	0
	Nurses	25	80.6			Nurses	31	100	
	Non N	18	90			Non N	20	100	
9	JB	39	36.4		9	JB	84	78.5	
	Joint	23	45.1	+8.7		Joint	45	88.2	+9.7
	Nurses	17	54.8			Nurses	28	90.3	
	Non N	6	30			Non N	17	85	
10	JB	52	48.6		10	JB	23	21.5	
	Joint	32	62.7	+14.1		Joint	25	49	+27.5
	Nurses	22	71			Nurses	15	48.4	
	Non N	10	50			Non N	10	50	
11	JB	36	33.6		11	JB	21	19.6	
	Joint	20	39.2	+5.6		Joint	21	41.2	+21.6
	Nurses	14	45.2			Nurses	16	51.6	
	Non N	6	30			Non N	5	25	
12	JB	12	11.2		12	JB	43	40.2	
	Joint	16	31.4	+20.2		Joint	46	90.2	+50
	Nurses	11	35.5			Nurses	28	90.3	
	Non N	5	25			Non N	18	90	
13	JB	39	36.4	28.3	13	JB	14	13.1	35.9
	Joint	33	64.7			Joint	25	49	
	Nurses	23	74.2			Nurses	16	51.6	
	Non N	10	50			Non N	9	45	
14	JB	59	55.1	13.5	14	JB	93	86.9	9.2
	Joint	35	68.6			Joint	49	96.1	
	Nurses	23	74.2			Nurses	29	93.5	
	Non N	12	60			Non N	20	100	
15	JB	34	31.6	11.5	15	JB	50	46.7	41.5
	Joint	22	43.1			Joint	45	88.2	
	Nurses	13	41.9			Nurses	28	90.3	
	Non N	9	45			Non N	17	85	
16	JB	24	22.4	40.3	16	JB	73	68.2	18.1
	Joint	32	62.7			Joint	44	86.3	
	Nurses	12	38.7			Nurses	27	87.1	
	Non N	20	100			Non N	17	85	
17	JB	28	26.2	3.2	17	JB	93	86.9	11.1
	Joint	15	29.4			Joint	50	98	
	Nurses	13	41.9			Nurses	31	100	
	Non N	2	10			Non N	19	95	
18	JB	22	20.6	24.5	18	JB	25	23.4	49.2
	Joint	23	45.1			Joint	37	72.6	
	Nurses	15	48.4			Nurses	23	74.2	
	Non N	8	40			Non N	14	70	
19	JB	18	16.8	12.6	19	JB	54	50.5	39.7
	Joint	15	29.4			Joint	46	90.2	
	Nurses	12	38.7			Nurses	28	90.3	
	Non N	3	15			Non N	18	90	
20	JB	11	10.3	30.9	20	JB	13	12.1	42.8
	Joint	21	41.2			Joint	28	54.9	
	Nurses	11	35.5			Nurses	15	48.4	
	Non N	10	50			Non N	13	65	

JB: Brooking's Professional Group (nurses n=107)
Joint: This Study's Professional Group (multidisciplinary team n=51)
Nurses: Qualified Nurses (n=14) plus Learner Nurses (n=17)
Non-Nurses: Medical Staff (n=11) plus Paramedical Staff (n=9).

Comparison of Multidisciplinary Team With Professional Group in Brooking (1986)'s Study for Subscale 2

Tables 42 and 43 show the items in rank order from the greatest change in positive attitude change to the greatest change in negative attitude for the multidisciplinary team compared to the nurses in Brooking's study.

With the exception of two items in the "Could be done by patient" list and one item in the "Could be done by relative" list, the multidisciplinary team showed more positive attitudes compared to the professional group of nurses in Brooking's study.

The two exceptions in the "Could be done by patient" list which showed less positive attitudes towards lay participation in care compared to Brooking's group were:

Item 3 Dressing and undressing the patient
Item 4 Cleaning the patient's teeth and mouth

The one exception in the "Could be done by relative" list which showed no change in attitude towards lay participation in care compared to Brooking's group was:

Item 8 Brushing the patient's hair

It would appear that the multidisciplinary team differed more in opinion compared to Brooking's group towards relatives getting involved in hospital care as opposed to patients getting involved in care. In particular from Tables 42 and 43, it can be seen that the multidisciplinary team under study held more positive attitudes (>25% different when compared to Brooking's group) towards items in the "Could be done by relative" list (11 items: 12,18,20,15,19,5,1,13,2,10,6). Whereas in the "Could be done by patient" list only 4 items revealed a >25% change in attitude (items: 16, 20, 13, 5).

Table 42: Care Activities in Hospital Scale - Could be Done By Patient

Items in rank order from the greatest change in positive attitude change to the greatest change in negative attitude for the multidisciplinary team compared to the nurses in Brooking(1986)'s study.

Could be done by the patient:

1	16. Helping the patient in or out of bed	+40.3%
2	20. Taking the temperature	+30.9%
3	13. Giving a suppository	+28.3%
4	5. Bringing or removing bedpan or bottle	+25.1%
5	6. Taking the pulse	+24.9%
6	18. Putting in ear-drops or eye-drops	+24.5%
7	12. Rubbing the patient's back or bottom	+20.2%
8	10. Testing the urine	+14.1%
9	14. Tidying the bedclothes or pillows	+13.5%
10	19. Assisting him taking a bath	+12.6%
11	1. Filling in the fluid chart	+12%
11	2. Applying ointment to the patient's skin	+12%
13	15. Washing the patient in bed	+11.5%
14	9. Helping the patient walk to the toilet	+8.7%
15	11. Giving an injection	+5.6%
16	8. Brushing the patient's hair	+3.7%
17	17. Making him comfortable in bed or chair	+3.2%
18	7. Helping the patient to eat or drink	+2.9%
19	4. Cleaning the patient's teeth or mouth	-4.3%
20	3. Dressing or undressing the patient	-5%

Table 43: Care Activities in Hospital Scale - Could be Done By Relative
Items in rank order from the greatest change in positive attitude change to the greatest change in negative attitude for the multidisciplinary team compared to the nurses in Brooking(1986)'s study.

Could be done by the relative:

1	12. Rubbing the patient's back or bottom	+50%
2	18. Putting in ear-drops or eye-drops	+49.2%
3	20. Taking the temperature	+42.8%
4	15. Washing the patient in bed	+41.5%
5	19. Assisting him taking a bath	+39.7%
6	5. Bringing or removing bedpan or bottle	+39%
7	1. Filling in the fluid chart	+37.7%
8	13. Giving a suppository	+35.9%
9	2. Applying ointment to the patient's skin	+33.5%
10	10. Testing the urine	+27.5%
11	6. Taking the pulse	+25.8%
12	11. Giving an injection	+21.6%
13	16. Helping the patient in or out of bed	+18.1%
14	17. Making him comfortable in bed or chair	+11.1%
15	9. Helping the patient walk to the toilet	+9.7%
16	14. Tidying the bedclothes or pillows	+9.2%
17	3. Dressing or undressing the patient	+7.8%
18	4. Cleaning the patient's teeth or mouth	+5%
19	7. Helping the patient to eat or drink	+4.7%
20	8. Brushing the patient's hair	0%

Comparison of Results Between Subgroups in Multidisciplinary Team for Subscale 2
An analysis of variance between the subgroups (qualified nurses n=14; learner nurses n=17; medical staff n=11; paramedical staff n=9) in the multidisciplinary team was measured using the Kruskal Wallis test.

Table 44 shows the mean ranks, Kruskal Wallis test statistic, and p-values that have been corrected for ties.

Table 44: Care Activities in Hospital Scale
Mean ranks, Kruskal Wallis test statistic, and p-values that have been corrected for ties.

Item	Mean Ranks	Mean Ranks	Mean Ranks	Mean Ranks	Kruskal Wallis	p-value
	Qualified Nurse	Learner Nurse	Medical Staff	Paramedical Staff		
1A	28.96	26.50	23.50	23.50	4.3012	0.2307
1B	25.00	25.00	29.64	25.00	7.4212	0.0596
1C	24.79	26.50	26.77	26.00	0.2135	0.9754
2A	27.14	26.50	25.82	23.50	1.3495	0.7174
2B	27.32	25.50	25.50	25.50	2.6429	0.4500
2C	25.46	24.50	31.59	22.83	3.9916	0.2624
3A	28.46	26.00	25.32	23.00	2.4856	0.4779
3B	24.00	24.00	28.64	29.67	6.7054	0.0819
3C	24.82	26.00	29.95	23.00	3.9574	0.2661
4A	27.96	27.00	22.50	25.33	2.6708	0.4452
4B	24.82	26.00	25.32	28.67	1.2863	0.7324
4C	21.64	27.00	27.27	29.33	2.8053	0.4226
5A	24.50	27.50	26.82	24.50	2.6515	0.4485
5B	20.46	24.00	26.59	37.67	10.6083	0.0140
5C	24.96	31.50	24.14	19.50	7.5234	0.0570
6A	26.00	26.00	26.00	26.00	0.0000	1.0000
6B	23.07	28.00	27.05	25.50	1.4170	0.7016
6C	21.75	28 50	29.86	23.17	4.0408	0.2571

Table 44: continued

7A	29.46	25.50	24.00	24.00	5.2622	0.1536
7B	24.61	23.00	22 45	38.17	10.2750	0.0164
7C	26.00	26.00	26.00	26.00	0.0000	1.0000
8A	27.96	27.00	22 50	25.33	2.6708	0.4452
8B	25.64	28.00	24 32	24.83	1.2899	0.7315
8C	26.00	26.00	26 00	26.00	0.0000	1.0000
9A	28.14	26.00	24.50	24.50	2.9762	0.3953
9B	21.11	25.50	25.91	34.67	6.1838	0.1030
9C	23.00	27.50	25.32	28.67	3.3895	0.3354
10A	25.50	27.00	25.50	25.50	2.0000	0.5724
10B	21.96	25.50	28.09	30.67	3.0725	0.3806
10C	22.11	29.50	24.59	27.17	2.7421	0.4331
11A	26.00	26.00	26.00	26.00	0.0000	1.0000
11B	21.43	27.00	29.05	27.50	2.7315	0.4349
11C	21.93	24.50	31.86	28.00	4.2610	0.2346
12A	25.82	25.50	28.64	24.00	2.4437	0.4856
12B	23.07	26.50	24.73	31.17	2.6778	0.4440
12C	25.32	26.50	28.14	23.50	1.9975	0.5729
13A	28.14	26.00	24.50	24.50	2.9762	0.3953
13B	24.29	23.00	23.95	36.83	8.5589	0.0358
13C	23.93	26.50	26.91	27.17	0.5168	0.9152
14A	27.64	27.00	24.00	24.00	2.8116	0.4216
14B	25.29	24.00	24.95	32.17	3.0071	0.3905
14C	25.00	28.00	25.00	25.00	4.0816	0.2528
15A	26.82	26.50	25.00	25.00	1.3484	0.7177
15B	26.07	26.50	20.77	31.33	3.4476	0.3276
15C	23.00	27.50	27.64	25.83	2.8171	0.4207
16A	26.82	26.50	25.00	25.00	1.3484	0.7177
16B	22.57	24.50	28.86	30.67	3.5514	0.3142
16C	22.50	28.50	27.14	25.33	3.7682	0.2876
17A	26.32	26.00	26.82	24.50	0.7914	0.8515
17B	22.57	23.00	31.18	30.67	5.8746	0.1179
17C	25.50	25.50	27.82	25.50	3.6364	0.3035
18A	26.82	26.50	25.00	25.00	1.3484	0.7177
18B	21.11	28.50	28.23	26.17	3.0217	0.3883
18C	22.64	28.00	30.59	21.83	4.6474	0.1995
19A	26.32	26.00	26.82	24.50	0.7914	0.8515
19B	22.57	24.50	28.86	30.67	3.5514	0.3142
19C	23.50	28.00	28.14	23.50	4.4664	0.2153
20A	26.00	26.00	26.00	26.00	0.0000	1.0000
20B	23.75	30.50	22.59	25.17	3.4187	0.3315
20C	23.61	31.00	21.45	25.83	4.4616	0.2157

A: "Could be done by nurse"
B: "Could be done by patient"
C: "Could be done by relative"

From this it can be seen that there was no significant differences between the subgroups of the multidisciplinary team except for the following isolated items:

Item 5 Bringing or removing bedpan or bottle (Could be done by patient)

Examination of the cross tabulation tables reveals that the paramedical staff and some of the medical staff tended not to tick this.

Item 7 Helping patient to eat and drink (Could be done by patient)

Examination of the cross tabulation tables reveals that the paramedical staff tended not to tick this.

Item 13 Giving a suppository (Could be done by patient)

Examination of the cross tabulation tables reveals that the paramedical staff tended not to tick this.

Subscale 3: "Nurses' Organisation of Care"

This subscale was completed by 31 members of the multidisciplinary team (qualified nurses n=14; learner nurses n=17). The medical staff and paramedical staff were not given this subscale as it was designed to examine the organisation of nursing as opposed to other health care. Table 45 shows the distribution of responses for each item for Brooking (1986)'s professional nursing group, this study's joint group of nurses and for the separate groups of qualified nurses and learner nurses. The point system mentioned above was not used to assess trends between Brooking's professional group and this study's participants on account of this scale only being given to the nurses and it being harder to degrees of positive and negative attitudes for responses "never", "sometimes", "often" and "always". As before, the missing out of the "Don't know" category with this study's participants also made comparison of groups more problematic.

Table 45: Nurses Organisation of Care Scale

Comparison of nurses group (qualified plus learner) with professional group (nurses) in Brooking (1986)'s study

Item	Group	No answer		Always		Often		Sometimes		Never		Points
		no.	%	no.	%	no.	%	no.	%	no.	%	
1*	JB	4	3.7	14	13.1 a	37	34.6 b	47	43.9 a	5	4.7 a	1xa+
	Nurse			6	20 -	7	23.3 +	16	53.3 +	1	3.3 -	2xa-
	Qual			4	30.8	2	15.4	6	46.2	1	7.7	1xb+
	Learn			2	11.8	5	29.4	10	58.8	0	0	=+1
2*	JB	0	0	0	0	1	0.9 a	57	53.3 a	49	45.8 a	1xa+
	Nurse			0	0	1	3.2 -	17	54.8 +	13	41.9 -	2xa-
	Qual			0	0	1	7.1	7	50.0	6	42.9	=-1
	Learn			0	0	0	0	10	58.8	7	41.2	
3*	JB	0	0	0	0	1	0.9 a	30	28 b	76	71 b	1xa+
	Nurse			0	0	0	0 +	3	9.7 -	28	90.3 +	1xb+
	Qual			0	0	0	0	3	21.4	11	78.6	1xb-
	Learn			0	0	0	0	0	0	17	100	=+1
4	JB	2	1.9	21	19.6 a	48	44.9 a	32	29.9 a	4	3.7 a	2xa+
	Nurse			4	12.9 -	15	48.4 +	10	32.2 -	2	6.5 -	3xa-
	Qual			1	7.1	8	57.1	5	35.7	0	0	=-1
	Learn			3	17.6	7	41.2	5	29.4	2	11.8	
5	JB	1	0.9	19	17.8 a	41	38.3 b	44	41.1 a	2	1.9 a	2xa+
	Nurse			3	9.7 -	16	51.6 +	12	38.7 +		+	1xa-
	Qual			1	7.1	6	42.9	7	50.0			1xb+
	Learn			2	11.8	10	58.8	5	29.4			=+3
6	JB	0	0	87	81.3 b	18	16.8 b	1	0.9 a	1	0 9 a	1xa+
	Nurse			20	64.5 -	10	32.3 +	1	3.2 -		+	1xa-
	Qual			7	50.0	6	42.9	1	7.1			1xb+
	Learn			13	76.5	4	23.5	0	0			1xb- =0

Table 45: continued

7	JB	3	2.8	25	23.4 b	34	31.8 a	40	37.4 b	5	4.7 a	2xa+
	Nurse			2	6.5 -	11	35.5 +	17	54.8 -	1	3.2 +	2xb-
	Qual			0	0	5	35.7	8	57.1	1	7.1	=-2
	Learn			2	11.8	6	35.3	9	52.9	0	0	
8*	JB	1	0.9	6	5.6 a	17	15.9 a	64	59.8 a	19	17.8 a	4xa+
	Nurse			0	0 +	4	12.9 +	19	61.3 +	8	25.8 +	=+4
	Qual			0	0	2	14.3	9	64.3	3	21.4	
	Learn			0	0	2	11.8	10	58.8	5	29.4	
Points					1xa+ 3xa- 2xb- =-6		4xa+ 1xa- 3xb+ =+9		4xa+ 2xa- 1xb- =0		4xa+ 3xa- 1xb+ =+3	13xa+ 9xa- 4xb+ 3xb- =+6

JB: Brooking's Professional Group (nurses n=107)
Nurse: This Study's Nurses (Qualified and Learners n=31)
Qual: Qualified Nurses (n=14)
Learn: Learner Nurses (n=17)

*: Indicates items that require a respondent to respond closer to "never" in order to show a positive attitude to lay participation in care

Code	Points	% Difference between Joint and JB	
+/-a	+/- 1	<10%	
+/-b	+/- 2	11-20%	
+/-c	+/- 3	21-30%	+ indicates more positive compared to JB
+/-d	+/- 4	31-40%	- indicates less positive compared to JB

Comparison of Results Between Subgroups in Nurses Joint Group for Subscale 3
An analysis of variance between the subgroups (qualified nurses n=14; learner nurses n=17) in the nurses joint group was measured using the Mann-Whitney test.

Table 46 shows the mean ranks, Mann-Whitney test statistic, and p-values that have been corrected for ties.

From this it can be seen that there was no significant differences between the subgroups of the nurses joint group except for the one isolated items.

Item 3 I discourage the family from doing anything for the patient while he or she is in the care of the hospital.

Examination of the cross tabulation tables reveals that the qualified nurses "sometimes" did as specified in item 3 whereas the learner nurses "never" did as specified in this item.

Table 46: Nurses' Organisation of Care Scale
Mean ranks, Mann-Whitney test statistic (Z statistic), and p-values that have been corrected for ties.

Item	Mean Ranks	Mean Ranks	Mann-Whitney	p-value
	Qualified Nurse	Learner Nurse	Z statistic	
1	14.85	16	-0.3908	0.6959
2	15.79	16.18	-0.1364	0.8915
3	14.18	17.50	-1.9756	0.0482
4	16.21	15.82	-0.1290	0.8973
5	14.18	17.50	-1.1286	0.2591
6	13.61	17.97	-1.5910	0.1116
7	14.36	17.35	-1.0266	0.3046
8	15.25	16.62	-0.4809	0.6306

Subscale 4: "Nurses' Attitudes Towards the Nursing Process Scale"
This subscale was completed by 31 members of the multidisciplinary team (qualified nurses n=14; learner nurses n=17). The medical staff and paramedical staff were not given this subscale as it was designed to examine the organisation of nursing as opposed to other health care. Table 47 shows the distribution of responses for each item for Brooking (1986)'s professional nursing group, this study's joint group of nurses and for the separate groups of qualified nurses and learner nurses. The point system mentioned above was not used to assess trends between Brooking's professional group and this study's participants on account of this scale only being given to the nurses and it being harder to degrees of positive and negative attitudes for responses "very good", "good", "no effect", "bad" and "very bad". As before, the missing out of the "Don't know" category with this study's participants also made comparison of groups more problematic.

Table 47: Nurses Attitudes Towards Nursing Process Scale
Comparison of nurses group (qualified plus learner) with professional group (nurses) in Brooking (1986)'s study

Item	Group	Don't Know		Very Good		Good		No Effect		Bad		Very Bad	
		No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
1	JB	19	18	15	14	50	47	22	20	1	1	0	0
	Nurse			4	13 3	19	63 3	6	20 0	1	3 3	0	0
	Qual			1	7 1	9	64 3	4	28 6	0	0	0	0
	Learn			3	18 8	10	62 5	2	12 5	1	6 3	0	0
2	JB	11	10	37	35	49	46	10	9	0	0	0	0
	Nurse			11	36 7	16	53 3	1	3 3	2	6.7	0	0
	Qual			6	46 2	7	53 8	0	0	0	0	0	0
	Learn			5	29 4	9	52 9	1	5 9	2	11.8	0	0
3	JB	6	6	29	27	57	53	15	14	0	0	0	0
	Nurse			13	41 9	16	51 6	2	6 5	0	0	0	0
	Qual			7	5	7	5 0	0	0	0	0	0	0
	Learn			6	35 3	9	52 9	2	11 8	0	0	0	0
4	JB	34	32	7	6	29	27	35	33	2	2	0	0
	Nurse			1	3 4	12	41 4	16	55 2	0	0	0	0
	Qual					5	41 7	7	58 3	0	0	0	0
	Learn			1	5 9	7	41 2	9	52 9		0	0	0
5	JB	11	1	28	26	48	45	20	19	0	0	0	0
	Nurse			6	51 6	13	41 9	2	6 5	0	0	0	0
	Qual			7	50	6	4_9	1	7 1	0	0	0	0
	Learn			9	52 9	7	41 2	1	5 9	0	0	0	0
6	JB	35	32	20	19	33	31	15	14	4	4	0	0
	Nurse			1	3 8	1	38 5	57 7	0		0	0	
	Qual			1	9 1	4	36 4	6	54.5	0	0	0	0
	Learn					6	4)	9	60	0	0	0	0
7	JB	18	17	16	15	3	36	32	3(	2	2		0
	Nurse			3	1 3	15	5 7	1	34 5	1	3 4	0	0
	Qual			2	15 4	5	38 5	5	38 5	1	7 7	0	0
	Lear			1	6 3	1	6	5	1 3				0
8	JB	11	1	-3	--	4	4	23	21	0		0	
	Nurse			8	2 8	2(	64 5	3	9 7				0
	Qual			4	28 6	1	7 4	0	0	0	0		0
	Learn			4	23 5	1	58 8	3	17 6	0	0	0	0
9	JB	-3	2	17		33	31	33	3	0		0	0
	N rse			2	6 7	5	5	3	4 3				
	Q				7	6	4 9	7	50				
	Lea n			1	6 3	9	56 3	6	37 5	0	0	0	

Table 47: continued

10	JB	13	12	26	24	48	45	16	15	3	3	0	0
	Nurse			5	6	8	58	6	19 4	2	6 5		
	Qual			2	14 3	9	64 3	3	2 4		0	0	
	Learn			3	7 6	9	52 9	3	17 6	2	11 8	0	0
11	JB	25	2.	6	6	23	2.	18	17	30	28	5	5
	Nurse	1	3 6			7	25 0	8	28 6	9	32 1	3	10 7
	Qual		0			3	25	3	25	4	33 3	2	16 7
	Learn	1	6 3		0	4	2	5	31 3	5	3 3	1	6 3

JB: Brooking's Professional Group (nurses n=107);
Nurse: This Study's Nurses (Qualified and Learners n=31)
Qual: Qualified Nurses (n=14);
Learn: Learner Nurses (n=17)

Comparison of Results Between Subgroups in Nurses Joint Group for Subscale 3
An analysis of variance between the subgroups (qualified nurses n=14; learner nurses n=17) in the nurses joint group was measured using the Mann-Whitney test.

Table 48 shows the mean ranks, Mann-Whitney test statistic, and p-values that have been corrected for ties.

From this it can be seen that there was no significant differences between the subgroups of the nurses joint group.

Table 48: Nurses' Attitudes Towards Nursing Process Scale
Mean ranks, Mann-Whitney test statistic (Z statistic), and p-values that have been corrected for ties.

Item	Mean Ranks	Mean Ranks	Mann-Whitney	p-value
	Qualified Nurse	Learner Nurse	Z statistic	
1	16.75	14.41	-0.8478	0.3966
2	13.27	17.21	-1.3573	0.1747
3	14.25	17.44	-1.0946	0.2737
4	15.67	14.53	-0.4058	0.6849
5	16.29	15.76	-0.1787	0.8582
6	12.82	14.00	-0.4488	0.6536
7	15.81	14.34	-0.5084	0.6112
8	14.50	17.24	-0.9864	0.3239
9	16.39	14.72	-0.5831	0.5598
10	15.43	16.47	-0.3565	0.7214
11	15.88	13.47	-0.7953	0.4265

Subscale 5: Official Policies Towards Some Nursing Issues
This section of the questionnaire was completed by 31 members of the multidisciplinary team (qualified nurses n=14; learner nurses n=17). The medical staff and paramedical staff were not given this part to complete as it was designed to examine the organisation of nursing as opposed to other health care. Table 49 shows the distribution of responses for each item in this study's joint group of nurses and for the separate groups of qualified nurses and learner nurses. This data was not compared to Brooking (1986)'s professional group responses as it was gathered more to supplement data on the use of the nursing process on the ward rather than measure attitudes towards patient participation in care.

Table 49: Official Policies Towards Some Nursing Issues
Distribution of scores for each item

	Joint Group		Qualified Nurses		Learner Nurses	
	No.	%	No.	%	No.	%
1: PPC						
a)Pol	14	50.0	6	50.0	8	50.0
No Pol.	4	14.3	4	33.3	0	0
No Ans	10	35.7	2	16.7	8	50.0
b)Taught	20	74.1	10	83.3	10	66.7
Not Tght	6	22.2	1	8.3	5	33.3
No Ans	1	3.7	1	8.3	0	0
2: RPC						
a)Pol	14	51 9	6	54.5	8	50.0
No Pol.	5	18 5	3	27.3	2	12.5
No Ans	8	29.6	2	18.2	6	37.5
b)Taught	19	70.4	8	72.7	11	68.8
Not Tght	5	18.5	1	9.1	4	25.0
No Ans	3	11.1	2	18.2	1	6.3
3: OwnC						
a)Pol	14	56	5	50.0	9	60.0
No Pol.	3	12.0	3	30.0	0	0
No Ans	8	32.0	2	20.0	6	40.0
b)Taught	16	72.7	6	75.0	10	71.4
Not Tght	3	13.6	1	12.5	2	14.3
No Ans	3	13.6	1	12.5	2	14.3
4: RelC						
a)Pol	14	56.0	7	70.0	7	46.7
No Pol.	4	16.0	3	30.0	1	6.7
No Ans	7	28.0	0	0	7	46.7
b)Taught	12	54.5	6	66.7	6	46.2
Not Tght	7	31.8	2	22.2	5	38.5
No Ans	3	13.6	1	11.1	2	15.4

I: PPC Issue One: The participation of patients in the planning of nursing care
a)Pol: Policy on ward b) Taught: Nurses taught c) No Ans: No answer
2: PRC Issue Two: The participation of relatives in the planning of nursing care
a)Pol: Policy on ward b) Taught: Nurses taught c) No Ans: No answer
3: Own Issue Three: The extent to which patients are encouraged to assist with their own nursing care
a)Pol: Policy on ward b) Taught: Nurses taught c) No Ans: No answer
4: RelC Issue Four: The extent to which relatives are encouraged to assist with the nursing care of the patient
a)Pol: Policy on ward b) Taught: Nurses taught c) No Ans: No answer

Comparison of Results Between Subgroups in Nurses Joint Group for Subscale 3
An analysis of variance between the subgroups (qualified nurses n=14; learner nurses n=17) in the nurses joint group was measured using the Mann-Whitney test.

Table 50 shows the mean ranks, Mann-Whitney test statistic, and p-values that have been corrected for ties.

From this it can be seen that there was no significant differences between the subgroups of the nurses joint group in their opinion about the existence of official policies towards some nursing issues on the ward. Generally 50 - 56% of participants claimed that official policies existed on the ward in relation to lay participation in care, although interestingly a fair proportion (28-35.7%) failed to give an answer, indicating a degree of uncertainty. Less uncertainty was shown towards the teaching about lay participation in care as only a few failed to give an answer to this question (3.7-13.6%). With the exception of teaching in relation to relatives being involved in care where only 54.5% said this occurred, lay participation in care was claimed to be taught in nurse training by 70.4-74.1% of respondents.

Table 50: Official Policies Towards Some Nursing Issues

Mean ranks, Mann-Whitney test statistic (Z statistic), and p-values that have been corrected for ties.

	Mean Ranks	Mean Ranks	Mann-Whitney	p-value
	Qualified	Learners	Z statistic	
Item 1				
a) PPC Pol	13.17	15.50	-0.8165	0.4042
b) Taught	12.96	14.83	-0.7986	0.4245
Item 2				
a) RPC Pol	13.00	14.69	-0.5960	0.5511
b) Taught	14.00	14.00	0.0000	1.0000
Item 3				
a)OwnCPol	12.85	13.10	-0.0935	0.9255
b) Taught	11.25	11.64	-0.1746	0.8614
Item 4				
a)RelCPol	10.20	14.87	-1.7369	0.0824
b) Taught	10.22	12.38	-0.8561	0.3919

I: PPC — Issue One: The participation of patients in the planning of nursing care
a)Pol: Policy on ward b) Taught: Nurses taught

2: PRC — Issue Two: The participation of relatives in the planning of nursing care
a)Pol: Policy on ward b) Taught: Nurses taught

3: OwnC — Issue Three: The extent to which patients are encouraged to assist with their own nursing care
a)Pol: Policy on ward b) Taught: Nurses taught

4: RelC — Issue Four: The extent to which relatives are encouraged to assist with the nursing care of the patient
a)Pol: Policy on ward b) Taught: Nurses taught

Table 51: Changes

In response to the question "What changes would you like to see made on Ward X which would encourage patients and their supporters (friends and relatives) to be more involved in their care in hospital?", the following suggestions were made:

Suggestions	Q4	Q3	J
Blank	6	7	13
Introduce named nurse (primary nursing)to ensure LPC offered	4	8	12
Improve communication with relatives and patients e.g. sheets and meetings	3	8	11
Involve lay people in care planning	1	9	10
Encourage relatives and friends to be involved in nursing e.g. feeding and beds	3	6	9
Involve all MDT in new approach (including students)		7	7
Need to improve inter professional communication	2	3	5
Involve relatives in treatment (professional must supervise)	3	1	4
Assess relatives' and patients' desire for involvement on admission	1	3	4
Change routine to encourage more individual approaches		4	4
More time for professionals to speak to lay people	1	2	3
Need to develop skills to educate and support lay people	1	2	3
Need more motivation to change from sister		3	3
Give better access to facilities e.g. kitchen	1	1	2
Lay presence on ward rounds and meetings to ask questions	1	1	2
Open visiting to allow free access to ward	1	1	2
New approach requires flexible management support and policy	2		2
Introduce new paperwork to facilitate LPC		2	2
Ward poster to inform people about LPC on ward		2	2
Special room for teaching lay people		2	2
Encourage relatives and friends to accompany patients e.g. physio	1		1
Allow to bring own things into hospital e.g. food and blankets	1		1
Multidisciplinary teaching to share common understandings	1		1
Designated areas of the ward for lay participation in care	1		1

Table 51: continued

Suggestions	Q4	Q3	J
Joint multidisciplinary notes on patients		1	1
Less conservative attitude from consultant		1	1
Health education leaflets to assist with patient education		1	1
Base change on Orem's model of nursing		1	1
All staff to do course on nursing process		1	1
Encouragement to read about the subject (research and books)		1	1

Q3: Nurses (qualified and unqualified); Q4: Multidisciplinary team
J: Nurses and multidisciplinary team

Table 52: Comments

In response to the question "Any further comments on the subject?", the following comments were made:

Comments	Q3	Q4	J
Blank	25	15	40
Lay people may not expect and not want to be involved in care	2	1	3
Do not assume lay people want to be involved in care		1	1
Don't make lay people feel pressurised to be involved		1	1
Existing systems of care are good no need for change		1	1
Friend and relative involvement only occasionally - supervised		1	1
Good ideal but professionals too busy		1	1
Needs to be part of training		1	1
Need whole hospital approach		1	1
Open visiting makes communication more difficult		1	1
Difficult to change practice in current ward structure		1	1
Fall in number of nurses will necessitate lay participation		1	1
Need to see all professionals and lay people as carers		1	1
Need to create a ward atmosphere that allows participation		1	1
LPC important in preparation for discharge	1		1
Some have no visitors to get involved	1		1
Friends and relatives important sources of patient information	1		1
LPC improves client-professional relations	1		1
Shouldn't make lay people feel guilty for not wanting LPC	1		1
Need better multidisciplinary teamwork for LPC	1		1
Need structured plan for LPC	1		1
Need careful assessment of capability	1		1
Patient involvement more important than relative involvement	1		1
Patient involvement already occurring on most wards	1		1
Lack time to involve lay people	1		1
Lack confidence to involve lay people	1		1
Need to educate lay people about what to expect	1		1

Q3: Nurses (qualified and unqualified); Q4: Multidisciplinary team
J: Nurses and multidisciplinary team

This question did not attract a lot of comment with many respondents (n=40) leaving it blank. The biggest issue appeared to be a concern that lay people may not want involvement in care.

APPENDIX XIX

FINDINGS FROM INITIAL INTERVIEWS

Introduction

This appendix contains tabulated summaries of the findings from the initial interviews. The aim of the initial interview was to ascertain health professionals' understanding of lay participation in care, identify what changes professionals wanted to make to their practice to facilitate lay participation in care and to establish what difficulties might be encountered when changing nursing practice on the ward.

Interview transcripts were individually analysed for issues and points raised in relation to questions asked, with the exception of the issue "State of the Ward" which emerged naturally from the data. Findings are described in terms of which issue and point was raised by which group of health professionals. Issues and points raised were then grouped into themes in order of importance based on the joint responses (medics, paramedics and nurses together). Those issues and points raised by more than 25% of participants in any one group have been highlighted in the tables. By giving such a detailed description of the findings in appendix it is hoped that the reader may be in a better position to judge validity of the conclusions drawn in the main thesis. By presenting the data in such detail it is intended that the descriptive statistics used should add a further dimension to, rather than detract from, the qualitative nature of the findings. In line with Miles and Huberman's (1984) approach to qualitative data analysis, the presentation of findings as descriptive tables should aid the reader to gain easy access to the data.

The descriptive tables will be presented under the headings of topics explored at interview. It should be noted that questions asked about lay participation in care did not differentiate between patients themselves and their family and friends getting more involved in care in hospital as this was thought to make the interview too cumbersome and was not thought to be important when looking at health professionals, attitudes to lay participation in care.

Table 53: Initial Interview: Participants' Career Details
N=Nurses (18), M=Medics (14), P=Paramedics (13), J=Joint (45)

Participants' Career Details	N %	M %	P %	J %
Trained at hospital under study	50	71		42
Trained at other London teaching hospital	17	14	46	24
Trained at hospital outside of London	33	14	54	33
Qualified for < 6 months	33	43	15	31
Qualified for 6 months - 1 year	6	14	15	11
Qualified for 1 year - 2 years	33		31	22
Qualified for 2 years - 5 years	6	14	38	18
Qualified for 5 years - 10 years				
Qualified for > 10 years	22	29		18
1st post since qualification	39		8	18
2nd post since qualification	39	29	15	29
Several posts since qualification	22	71	77	53
Experience of working in other hospitals	44	71	69	60

Table 54: Initial Interview: Previous experience of lay participation in care
N=Nurses (18), M=Medics (14), P=Paramedics (13), J=Joint (45)

Previous Experience of Lay Participation in Care	N %	M %	P %	J %
Rehabilitation	11	7	38	18
None	17	29		15
Not in formal way		36	8	13
Part of the Job		7	38	13
Pre Discharge		21	15	11
Paediatrics	17		8	9
Dying	17			7
Orem's Model	17			7
Relative initiated		14	8	7
HIV and AIDS	5	14		7
Neurological		7	15	7
Odd cases	17			7
Discuss emotional issues			15	4
Elderly	5	7		4
Chemotherapy and Radiotherapy	5		8	4
Self catheterisation	11			4
Use volunteers			8	2
Training	5			2
Diabetes	5			2
Abroad		7		2
Alcoholics		7		2
Dermatology			8	2
Home parental nutrition		7		2
Amputation		7		2
Haematology		7		2
Day hospital			8	2
Hernia	5			2
Burns and Plastics	5			2
Chronic care	5			2
Nursing process	5			2

Table 55: Initial Interview: Advantages - patients' perspective
NB. 45 points and issues raised grouped into 10 overall themes (miscellaneous=1)
N=Nurses (18), M=Medics (14), P=Paramedics (13), J=Joint (45)

Improved outcome in long term	**N %**	**M %**	**P %**	**J %**
Well looked after at home - continuity of care	33	43	46	40
Prevent complications - anticipate problems	6	14	15	11
Better at care in the long term		7	15	7
Improves prognosis - stops collusion in alcoholism		14	8	7
Prevents readmission		14	8	7
Improves general health		7		2
Better standard of care	**N %**	**M %**	**P %**	**J %**
Relative give better care - more time, more interest	33	43	38	38
Give more individualised care - not loose identity	33	7		16
Relative can keep more careful eye on patient	6	7		4
More natural for patient to administer care		7		2
Improves recovery	**N %**	**M %**	**P %**	**J %**
Improves recovery - compliance and control over disease	50	29	31	38
Relatives can direct their efforts better - understand more		21	15	11
Someone else knows about condition if something goes wrong		14	8	7
Better experience of being in hospital	**N %**	**M %**	**P %**	**J %**
Less frightened - more relaxed	33	21	38	31
Feel closer to relative than nurse	50	7	8	24
Prefer to be looked after by someone know well - personal things	17	14	23	18
Feel someone helping - supported emotionally		21	38	18
Better cope if can share experience with relative	22			9
Feel less bored - extra stimulation		14	8	7
Better understood by relative - treated more sympathetically		7		2
Settle quicker in hospital - ease passage		7		2
Protect patient from victimisation	6			2
Better understanding and better informed	**N %**	**M %**	**P %**	**J %**
More knowledgeable about illness and treatment	22	36	23	27
More knowledgeable about what is going on	6	14	8	9
More educational - can identify misunderstandings			15	4
Know what to expect		7		2
Know how to look after themselves			8	2
Encourages them to think	6			2
Feel more in control	**N %**	**M %**	**P %**	**J %**
Enjoy autonomy - feel more in control	22	14		13
Most want to know diagnosis - want to plan care		14	31	13
Become more responsible for own care		21	15	11
Have a go between - more able to ask questions	6	7	15	9
Stronger sense of achievement		14		4

Table 55: continued

Better prepared for discharge	**N %**	**M %**	**P %**	**J %**
Better prepared for discharge - less scared	28			11
More confident in care being given by relative or self -better able to cope with illness	22	21	23	22
Know when to consult G.P.		14		4
Help adjust to more dependent role	6		8	4
Education of family crucial e.g. diet		7		2
Encourages sense of well-being	**N %**	**M %**	**P %**	**J %**
Positive thing - more content	11	21	15	16
Feel more motivated		7	8	4
Improves morale	6			2
Good for family relationship	**N %**	**M %**	**P %**	**J %**
Relative understands patient more - good for their relationship		14	8	7
Better relationship with professionals	**N %**	**M %**	**P %**	**J %**
Makes relationship with staff easier	11	7		7
Stops misunderstandings - foreign patients		7		2
Relative can help overcome barriers in hospital e.g. class, age	6			2
Miscellaneous	**N %**	**M %**	**P %**	**J %**
Good idea for young alert and intelligent	11			4

Table 56: Initial Interview: Advantage - relatives' perspective

NB. 43 issues and points raised grouped into 12 overall themes (miscellaneous=5)
N=Nurses (18), M=Medics (14), P=Paramedics (13), J=Joint (45)

Better experience of being in hospital	**N %**	**M %**	**P %**	**J %**
More positive role to play - feel less inadequate	78	43	62	62
Put mind at rest - know what is happening		29	38	20
Good to be prepared - know what to expect	11	7	31	16
Better prepared for discharge	**N %**	**M %**	**P %**	**J %**
Know what to do after discharge	17		54	22
Gives confidence		14	15	9
Build up desire to care		7		2
Build up ability to care	6	14		7
Can assess own limitations and plan strategies			8	2
Can prevent problems			8	2
Better continuity	**N %**	**M %**	**P %**	**J %**
More likely to continue after discharge	44	21	8	27
Continuity of care from home			15	4

Table 56: continued

Better understanding and informed	**N %**	**M %**	**P %**	**J %**
Better understanding of disease and treatment	17	14	38	22
Better informed as to what is happening	17	21	15	18
Adjust better to illness	**N %**	**M %**	**P %**	**J %**
Help come to terms with illness	22	7	8	13
Patient knows more-needs less reassurance		7		2
Breaks down barriers which inhibit coping	6			2
Feel more in control	**N %**	**M %**	**P %**	**J %**
More control over situation	11	7	23	13
Feel contributing to recovery - feel better	22		8	11
Want to know what is going on		7	8	4
Feel done their duty - if patient dies		14		4
Can act as patient's advocate			15	4
Retain ability to care		14		2
Miscellaneous	**N %**	**M %**	**P %**	**J %**
Easier with practice			8	2
Cheaper - less cost in fares to the hospital	6			2
Good way of communicating with the community	6			2
Can comment on what they see	6			2
Can talk in more depth about health	6			2
Good for family relationship	**N %**	**M %**	**P %**	**J %**
Binds family together	17	7		9
Good for relationship with patient		14		4
Patient more involved-less for family to do		7		2
Nothing - little advantage	**N %**	**M %**	**P %**	**J %**
Little advantage		21	8	9
Better standard of care	**N %**	**M %**	**P %**	**J %**
Feel can give better care	6	14		7
Better able to encourage patient			15	4
Better for patient to be more independent			8	2
Less likely to harm themselves			8	2
Can give more support emotionally and physically			8	2
Can spend more time with patient	6			2
Better relationship with professionals	**N %**	**M %**	**P %**	**J %**
Better relationship with staff - more sympathy	6	14	15	11
Less confusion if patient knows what is happening		7		2
Better communication			8	2
Feel more able to ask questions - in depth			8	2

Table 56: continued

Endless benefits	**N %**	**M %**	**P %**	**J %**
Endless benefits-provided done properly			8	2
Encourage sense of well being	**N %**	**M %**	**P %**	**J %**
Can talk in more depth about health	6			2

Table 57: Initial Interview: Advantage - professionals' perspective

NB. 44 issues and points raised grouped into 12 overall themes (miscellaneous=5)
N=Nurses (18), M=Medics (14), P=Paramedics (13), J=Joint (45)

Improved discharge arrangements	**N %**	**M %**	**P %**	**J %**
Easier to make discharge arrangements	**50**	7	**31**	**31**
Sense of relief-know can cope			15	4
Improve knowledge about use of aids after discharge			8	2
Less problems getting people home	6			2
Cost effective-solves problem of lack of resources	**N %**	**M %**	**P %**	**J %**
Economic necessity - lack of manpower and resources	11	**43**	**38**	**29**
Wouldn't need to attend physiotherapy out-patients and less district nursing required	6	21	8	11
Saves time if patient knows what doing			15	4
Help to resolve practical problems e.g. lack of clean sheets	6			2
Better relationship with professional	**N %**	**M %**	**P %**	**J %**
More aware, better informed-easier to relate to	**33**	**36**	8	**27**
Easier in long term-plan together and share goals		**29**	8	11
Break down lay and professional barriers-share concerns	6	7	15	9
Better rapport-teach better	17			7
Reduce misunderstanding - know why treatment done		7	8	4
Appreciate professional's difficulties more		7		2
Know when to contact the medic		7	8	4
Reduces workload - can give better care	**N %**	**M %**	**P %**	**J %**
Takes routine work off nurses-reduces workload	**39**	14		20
Frees nurses to do things for other patients	22	21	15	20
Frees nurses to talk to more patients	6	21		9
Reduce need for social meeting	6			2
Get to know more about individual patients	**N %**	**M %**	**P %**	**J %**
Can give better histories-learn more from relatives about home	22	7	**46**	24
Better feedback	11	14		9
Better feedback in out-patients		7		2
Relatives know patient better than professional			15	4
Know who knows what	6			2

Table 57: continued

Better compliance	N %	M %	P %	J %
Care more likely to be sustained at home, monitored		29	31	18
Patient more co-operative and compliant -job easier		36	23	18
Relatives can reinforce professional view			8	2
Makes future treatment easier	6			2
Better care	N %	M %	P %	J %
Relatives more likely to carry out treatment-better care		21	23	13
More individualised care-more holistic care	17	7	8	11
Leave hospital earlier-better quicker		14	15	9
Help with observations-do them more accurately		14		4
Less task oriented care	6			2
Improved outcome in long term	N %	M %	P %	J %
Less chance of patient returning with complications	11	14	15	13
Lots of advantages	28		8	13
Better team approach	N %	M %	P %	J %
Better multidisciplinary team approach	17		15	11
Miscellaneous	N %	M %	P %	J %
Challenge of something - improve care	17			7
Medics less threatened-more informed to make decisions		7		2
Stops collusion in families e.g. alcoholism	6		8	4
Improve rapport with community	6			2
Increases professionalism	6			2
No disadvantages		7		2
Better able to deal with emotional problems	N %	M %	P %	J %
Relieves burden of emotional care		7		2
Develop counselling skills-deal with emotional problems			8	2

Table 58: Initial Interview: Disadvantage - patients' perspective

NB. 46 issues and points raised grouped into 10 overall themes (miscellaneous=2)
N=Nurses (18), M=Medics (14), P=Paramedics (13), J=Joint (45)

Invasion of Privacy and Independence	N %	M %	P %	J %
May not like closeness with family - too personal	39	29	31	33
Seen as an intrusion - not want the attention	6	36	23	20
May feel confidentiality at risk	33		31	22
May not like independence being taken away		14	8	7
Not enough time and space to be on own	6		15	7
May not want to be seen when ill	6			2
Nurse may involve family without consultation	6			2

Table 58: continued

Lay care not as good as professional care	**N %**	**M %**	**P %**	**J %**
May not see care as good as professional care	**39**	**29**	**31**	**33**
Relatives too caring - may loose independence	17	7	**38**	20
Fear do harm	17	21	15	18
May not be capable of involvement	11	7	23	13
May forget to do care - confused and memory loss	11	7		7
Misunderstand -not trained sufficiently		14		4
May prefer someone more distant - easier to be honest			8	2
May be neglected if self caring	6			2
Intrusion on own and/or others lives	**N %**	**M %**	**P %**	**J %**
Given too much to do - burden	**44**		8	20
May not like to inflict self on others	11	7	8	9
Family conflict	**N %**	**M %**	**P %**	**J %**
May not get on with family	11	21	**31**	20
May welcome break from family - enjoy hospital		14	8	7
Conflict - if patient disagrees with relative e.g. re. prognosis		7	**31**	11
May change relationship with relative - strain	6	7	15	9
May become fed up with illness		7		2
Misunderstandings if family give care wrongly			8	2
Participation not part of patient role	**N %**	**M %**	**P %**	**J %**
Patient role is passive-professional paid to do job	17	21	15	18
May not be motivated towards involvement and prevention		21	**31**	16
Don't see relevance - block involvement and not want it	22	7		11
No Disadvantages for Patient	6	21	8	11
Participation may cause more anxiety	**N %**	**M %**	**P %**	**J %**
May not want to hear prognosis		14	8	7
May upset patient because know too much			23	7
Worried about taking responsibility for illness-scared	17	14	8	13
In hospital got other things to think about			8	2
Want to pretend there is no problem			8	2
May become hypochondriac, neurotic and anxious	6	14		7
Feel failure if can't manage - reluctant to admit	11			4
Can put patient off -too much information		7		2
Unable to participate	**N %**	**M %**	**P %**	**J %**
May be too sick	17	7	8	11
May have no relations	3		2	5
May be afraid to ask questions -too anxious		14	1	3
Insufficient time to adjust to illness			1	1

Table 58: continued

Not capable of participation	**N %**	**M %**	**P %**	**J %**
Don't understand treatment and condition		14	8	7
Not intelligent enough to understand	6	14		7
May not be able to decide what information important		7	8	4
Miscellaneous	**N %**	**M %**	**P %**	**J %**
May feel left out if everyone has visitors	6	14		7
Relatives may be in conflict with medicine		7		2
Professional loss of control	**N %**	**M %**	**P %**	**J %**
May be discharged into community without commitment		14		4
Loss of contact with nursing staff		7		2

Table 59: Initial Interview: Disadvantage - relatives' perspective

NB. 41 issues and points grouped into 11 overall themes (miscellaneous=5)
N=Nurses (18), M=Medics (14), P=Paramedics (13), J=Joint (45)

Unable to participate	**N %**	**M %**	**P %**	**J %**
May work - can't visit	50	43	54	49
Geographically live too far away	28		8	13
Intrusion on own and/or others life	**N %**	**M %**	**P %**	**J %**
Takes time and effort-burden and intrusion on own life	50	29	54	44
May misunderstand what is needed-what taking on	11	7	31	13
Might need a break - respite care				
May give up if asked to do more-burden		14	8	7
Not prepared to do it all the time-too much		14		4
Invasion of Privacy and Independence	**N %**	**M %**	**P %**	**J %**
May not like closeness - too personal	6	7	8	7
Confidentiality - patient may not want relative to know	6	7		4
Participation may cause more anxiety	**N %**	**M %**	**P %**	**J %**
Frightened to take responsibility - anxious	39	36	46	40
Too concerned - may create anxiety			15	4
Feel failed if patient doesn't improve - fault				2
Fear technical aspects - blinded by science	17			7
Feel guilty admitting don't understand			8	2
Feel forced to get involved	**N %**	**M %**	**P %**	**J %**
Feel forced and obliged to get involved	61	36	15	40

Table 59 continued

Participation not part of patient role	**N %**	**M %**	**P %**	**J %**
Paid taxes-expect professional to give care	44	29	38	38
Cultural - not used to participating	11			4
Don't tend to look after the elderly in society	11			4
May feel getting in the way		7	8	4
Feel putting people out of jobs		7		2
Lay care not as good as professional care	**N %**	**M %**	**P %**	**J %**
Don't feel capable-feel might do harm	44	14	46	36
Can get over enthusiastic			8	2
Not like hospitals and illness	**N %**	**M %**	**P %**	**J %**
May not have tolerance for disease and hospitals	22	7	38	22
Caring can be stressful e.g. AIDS	17			7
Family conflict	**N %**	**M %**	**P %**	**J %**
May not get on with relative	6	7	15	9
May resent patient having illness		7		2
Requires a change in role for some	6		8	4
Patient too dependent on relative			8	2
Lead to conflict if give care wrongly			15	4
May effect rest of family			15	4
Feel patient will be different out of hospital			8	2
May feel hurt if not wanted by patient	6			2
No disadvantage for relative	6	7		4
Unable to participate	**N %**	**M %**	**P %**	**J %**
Too tired - own illness - not capable		7	8	4
May have no facilities, money and resources	6			2
Miscellaneous	**N %**	**M %**	**P %**	**J %**
Could sabotage treatment plan			8	2
Not understand medical jargon			8	2
May be left to get on unsupported			8	2
Not understand roles of multidisciplinary team			8	2
Perceived as trying to save money - political	6			2
Not want participation	**N %**	**M %**	**P %**	**J %**
May feel futile to be involved	6			2
May not want to try anything new	6			2

Table 60: Initial Interview: Disadvantage - professionals' perspective

NB. 67 issues and points grouped into 12 overall themes (miscellaneous=10)
M=Medics =(14), P=Paramedics (13), N=Nurses (18), J=Joint (45)

Time consuming and increased workload	**N %**	**M %**	**P %**	**J %**
Takes time to educate	50	36	46	44
Too time consuming to communicate with everyone	17	29	46	29
Lots of work initially	22			9
Won't make life easier-pressure on beds		7	15	7
Tend to work on short term-quicker	17			7
Difficult to implement	17			7
Need re-education to think differently			15	4
New dimension to job ? too much	11			4
Slow process and then may change mind		7		2
Too much paperwork		7		2
More work for nurses in checking		7		2
Interrupt ward routine and practice	**N %**	**M %**	**P %**	**J %**
Could slow things down on the ward-interrupt routine	28	29	31	29
May get under nurses' feet	11	36	38	27
Anxious relatives may annoy and impede progress		7	31	11
Difficult to have so many visitors in hospital		14	8	7
Dislike change		7		2
Erosion of professional role	**N %**	**M %**	**P %**	**J %**
May feel functions being eroded away	28	36		22
May say something don't want relatives to hear	17	7	15	13
Enough trouble determining roles inter professionally		7		2
Unions may object to jobs being taken away		7		2
Doubt lay competence	**N %**	**M %**	**P %**	**J %**
May do harm to patient-not know what doing		21	46	20
Lay lack of understanding - simplistic		14	31	13
May be willing but not capable		21	8	9
Hard to maintain standards	22			9
Overestimate and underestimate ability to give care			15	4
Inaccurate monitoring-detrimental		14		4
May lack physical ability		7	8	4
Lay people not experienced enough to assess		7	8	4
May be encouraging something that does more harm		7		2
Concern for liability if something goes wrong	**N %**	**M %**	**P %**	**J %**
Liability if something goes wrong	39	7	8	20
Can't rely on task being done-fear passing on responsibility	11	7		7

Table 60: continued

Lay and Professional conflict	**N %**	**M %**	**P %**	**J %**
Relatives may contradict medics		14	38	16
Relatives may be more demanding-ask too many questions	17	14	15	16
Professional may feel more vulnerable and open to criticism	6	21	23	16
Patients will expect professionals to justify decisions	17	14		11
Advice could be misconstrued		7	31	11
Relative too protective-discourage independence	6		15	7
Clash of personalities-hard to get on with some relatives	6		15	7
Patients may hide things		7	8	4
May play professionals off one against the other			15	4
May lead to more complaints			8	2
May misinterpret non involvement - judgmental	6			2
No disadvantages	6	21	15	13
Don't like to pressurise relatives into care	**N %**	**M %**	**P %**	**J %**
Difficult if relative doesn't want involvement - don't like to pressurise		29	15	13
May lack motivation		7	8	4
Relatives not persuasive enough	6			2
Relatives may interfere with good care being given	**N %**	**M %**	**P %**	**J %**
Can't get message to patient-family in the way	11	7	8	9
Other things on ward of more priority	11		8	7
Difficult to know how far to take participation	**N %**	**M %**	**P %**	**J %**
Difficult to know how much to tell		7	23	9
Getting balance right is hard			15	4
Difficult to treat people individually		7		1
Professionals feel uncomfortable talking to lay people	**N %**	**M %**	**P %**	**J %**
May feel uncomfortable talking to relatives-don't know how to answer questions	17		8	9
Miscellaneous	**N %**	**M %**	**P %**	**J %**
Not enough room for everyone		7		2
Difficult to know who visitors are and what doing		7		2
May be repercussions for rest of hospital			8	2
Some relatives collude e.g. alcoholics			8	2
Difficult if discover can't cope			8	2
Relative may not agree to take home- may cost more			8	2
Need re-education to think differently	11			4
Hierarchy may see it as way to cut back	6			2
Doesn't solve problem of those without relatives	6			2
Less time to teach students	6			2

Table 60: continued

Less contact with patient - not know what is happening - lack of monitoring	N %	M %	P %	J %
Professional get less involved-carer doing everything	6		8	4
Professional get less involved - carer take over				
Can't tell if patient is being monitored accurately		7		2
Relatives not communicating back	6			2
Nurses naturally check patients' care, but can relatives?	6			2

Table 61: Initial Interview: Desired changes to facilitate lay participation in care

NB. 167 issues and points grouped into 27 grouped themes (miscellaneous=14)
N=Nurses (18), M=Medics (14), P=Paramedics (13), J=Joint (45)

Emphasise teaching role	N %	M %	P %	J %
Explain, educate, inform, support	56	21	46	42
Drug therapy education	22	7	15	16
Build up confidence, desire and ability to care		21		7
Health education - teach whole family to develop skills		7	15	7
Introduce medicine reminder card system		14	8	7
Teach health care positively	17			7
Teach about disease	11			4
Educate to adopt a different lifestyle			8	2
Re-educate about nurses' role	6			2
Offer teaching sessions to relatives	6			2
Become more available	**N %**	**M %**	**P %**	**J %**
Build up contact with relatives - more approachable	28	36	46	36
Take more time to talk - reorder priorities	6	14	38	18
Encourage questions by being present on ward rounds	11	21	8	13
Ensure have time to discuss - known time	17	14	8	13
Easily be able to get in touch with staff - phone	6	7	15	9
Provide forms to fill in if want information from staff			8	2
Flexible working times - more available to meet relatives			8	2
Encourage independence	6			2
Involve lay people in basic nursing care	**N %**	**M %**	**P %**	**J %**
Involve in bathing, washing and dressing	33	36	31	33
Involve in lifting, transferring and mobilising	22	7	31	20
Encourage eating - help feeding	17	14	8	13
Make comfortable in bed	28			11
Involve in toilet training and toileting	6	14		7
Involve in turning-pressure area care		14		4
Involve in first aid care		7		2
Give out the tea			8	2
Help with reading	6			2

Table 61: continued

Create atmosphere conducive to participation	**N %**	**M %**	**P %**	**J %**
Offer autonomy, privacy and respect		7	31	11
Make clear - part of team and can get involved	28	29	23	27
Need to change attitudes- empathise more	17			7
Open access to charts and notes for patients	6		15	7
Encourage questions	11			4
Be innovative	6			2
Be open to criticism	6			2
Break through bureaucracy	6			2
Monitor and check up	**N %**	**M %**	**P %**	**J %**
Closely monitor and check up - after discharge	33	29	31	31
Need back up from GP - lifeline in community		14	23	11
Check before discharge capable of taking over care		7	23	9
Ensure adequate supervision is given	11			4
Improve communication - humanise care	**N %**	**M %**	**P %**	**J %**
Improve communication - know what is happening	17	64	15	31
Relieve emotional burden		14	8	7
Avoid medical jargon - humanise care		7	15	7
Multidisciplinary team should give information			8	2
Be a good listener	6			2
Ensure good multidisciplinary team work	**N %**	**M %**	**P %**	**J %**
Have regular meetings	22	21	46	29
Involve district nurse in discharge planning	11			4
Involve everyone - including cleaners			15	4
Multidisciplinary team to attend ward round		7		2
Nurses refer to specialists e.g. pharmacist			8	2
Share one system of notes for multidisciplinary team			8	2
Ensure not too many people are involved			8	2
Involve lay people with dietician			8	2
Nurse to act as go-between for professionals			8	2
Communication sheet for multidisciplinary team			8	2
Hold inter-disciplinary lectures			8	2
Team discussion and agreement on aims and methods			8	2
Team needs to say same thing			1	2
Ensure nurses more aware - not in the dark	6			2
Daily handover with medics	6			2
Junior medics should get involved more	6			2
Nurses need to be more assertive with medics	6			2
Offer participation in care as a free option	**N %**	**M %**	**P %**	**J %**
Feel able to withdraw - not forced	33	29	15	31
Patient should decide if want others involved		7	23	9
Not off load care	17			7
May need respite care		7		2
Ensure confidentiality - under patient control			8	2
Initiation should come from relatives not professionals	6			2

Table 61: continued

Involve in care planning	**N %**	**M %**	**P %**	**J %**
Discuss plan of care with patient and relative	39	14	23	27
Involve in social meetings - case conferences		7	23	9
Joint meetings with patients			8	2
Plan discharge early and communicate plan			8	2
Not just physical care, decision making too	6			2
Care plans at bottom of bed	6			2
Involve in own admission assessment	6			2
Individualise care	**N %**	**M %**	**P %**	**J %**
Tailor participation for individual	56	7		24
Assess individual's desire and ability for involvement in care		29	46	22
Target people to be involved	6	14	15	11
Don't apply it to everyone - ask what want	11	7		7
Provide adequate facilities and resources	**N %**	**M %**	**P %**	**J %**
Good facilities - somewhere to stay (quiet room)	11	21	38	22
Provide booklets to supplement verbal teaching	6	14	8	9
Provide links with local self help groups	6	7	15	9
Need more people to teach			8	1
Adequate staff to supervise	6			1
Bell system to call own nurse	6			1
Change the documentation	6			1
Change organisation of ward	**N %**	**M %**	**P %**	**J %**
Introduce different system of nursing e.g. Primary Nursing	44	7	8	22
Key workers to co-ordinate and liaise with families	6		38	13
Separate teaching from business ward rounds		14	8	7
Ensure adequate handover - formal, written		7	8	4
Offer clear guidelines and explanations	**N %**	**M %**	**P %**	**J %**
Give guidelines to ensure policy effective	17	21	23	20
Roles need to be defined and demarked		7	38	13
Make people aware of changes - prepare and monitor		14	8	7
Written information on what lay participation in care is		7		2
Give specific jobs to do		7		2
Organise a system of priorities		7		2
Need to know what is involved beforehand		7		2
Need to explain reasons for involvement			8	2
Need to know what LPC means	6			2
Involve in monitoring condition	**N %**	**M %**	**P %**	**J %**
Involve in doing observations e g. BP, F/B, stools, wt, urine	28	29		20
Involve in doing blood sugar monitoring	11			4
Empty catheter bag	11			4

Table 61: continued

Involve in paramedical therapy	**N %**	**M %**	**P %**	**J %**
Go with patient to speech therapy, physiotherapy	17	21	15	18
Introduce change sensitively	**N %**	**M %**	**P %**	**J %**
Slowly educate - less threatening	28	7	8	16
Change attitudes - positive feedback - open to change	11	7	15	11
Introduce change in small steps - careful planning, not too ambitious		14		4
Need a trial period		7	8	4
Offer a long term programme	6		8	4
Introduce gradually by disease process		7		2
Discussion on aims and methods			8	2
Involve charge nurse in a supportive way	6			2
Involve in treatment	**N %**	**M %**	**P %**	**J %**
Self medication	28	14		16
Assist with medications - monitor pain control		29	8	11
Dressings and wound care		21	8	9
Assist with nasogastric feeding	6		8	4
Administer prednisolone enema	6			2
Self administrate nebulisers	6			2
Involve in rehabilitation	6			2
Catheter care - change catheters	6			2
Encourage lay presence in hospital	**N %**	**M %**	**P %**	**J %**
Open visiting	17	21		13
Encourage partners to come into clinic with patient			8	2
Explore use of volunteers	6			2
Involve relatives from the beginning	6			2
Encourage homelike atmosphere	**N %**	**M %**	**P %**	**J %**
Bring food in	11	14	8	11
Care in hospital as would at home	6	7	8	7
Involve in domestic tasks as at home e.g. bed making		14		4
Take home for weekend leave	6			2
Restrict information to lay people	**N %**	**M %**	**P %**	**J %**
Limit information given so as not to put off		7	15	7
Don't tell patient what doesn't want to hear		14	8	7
Not sure what changes should be made	**N %**	**M %**	**P %**	**J %**
Don't know		14	8	7
No suggestions - already involved enough	6			2

Table 61: continued

Miscellaneous	N %	M %	P %	J %
Involve other patients - talking, flower arranging	6		8	4
Pre-admission preparation for hospital	11			4
Get round legal implications		7		2
Persuade people to change		7		2
Better on different ward with different management		7		2
Involve patients in own care not relatives			8	2
Acknowledge personality clashes			8	2
Act as advocate for the patient			8	2
Use complementary therapies more	6			2
Set up grievance committee	6			2
Important to document care	6			2
Involve family if problems	6			2
Need to get balance right	6			2
Need to be more professional	6			2
Ensure staff are adequately trained	**N %**	**M %**	**P %**	**J %**
Assess student knowledge of lay participation and teach	17			7
Introduce concept before qualifying - make medics more aware		14		4
Teach nurses how to teach - careful training			15	4
Need everyone's commitment - introduce before join ward			8	2
Restrict participation in practical care	**N %**	**M %**	**P %**	**J %**
Not allowed to participate in wound dressings	11			4
Ask lay persons to withdraw if carrying out procedures		7		2
Key figures need to be committed to changes	**N %**	**M %**	**P %**	**J %**
Need leader to organise change	11		8	7
Ensure support from registrar level			15	4
Consult with permanent head to change things		7		2
Assess if team wants change		7		2
Need to change from the top - medics as well			8	2
Need to get to know social situation better	**N %**	**M %**	**P %**	**J %**
Need to know more about their backgrounds			23	7
Identify carer after discharge		7		2
Be aware of family dynamics			8	2
Professional should control the situation	**N %**	**M %**	**P %**	**J %**
Nurses should control visiting		7		2
Relative should be flexible to fit in with routines		7		2
Inform about hospital routines		7		2

Table 61: continued

N=Nurses (18), M=Medics (14), P=Paramedics (13), J=Joint (45) **Establish group work on the ward**	N %	M %	P %	J %
Set up groups for assertiveness training			8	2
Set up alcoholics anonymous groups			8	2
Groups for the elderly - run as day centre with volunteers			8	2
Group evaluation of progress	6			2

Table 62: Initial Interview: Ward ready for change

N=Nurses (18), M=Medics (14), P=Paramedics (13), J=Joint (45)

	N %	M %	P %	J %
Yes	**72**	**79**	**77**	**76**
Not sure	22	14	23	20
No	6	7		4
Ward needs to change	N %	M %	P %	J %
Worth trying - needs improvement - not efficient	28	21	**31**	27
Not enough change in the past	N %	M %	P %	J %
In a rut - not enough change in the past	**39**	14		20
not geared towards changing ways completely	6			2
Ward should change	N %	M %	P %	J %
Can't leave things static - should change	17	14	31	20
Communication needs improving	17			7
Need to change attitudes	17			7
Good for patients	11			4
Should evaluate care	6			2
Change will help existing problems	6			2
Staff enthusiastic for change	N %	M %	P %	J %
Some staff enthusiastic for change	50			20
New staff on ward-get better response	22			9
Ward receptive to change		14		4
Ideal ward for change	6			2
Can't comment - don't know ward well enough	6	14	38	18
Expected to change	N %	M %	P %	J %
General atmosphere of NHS - constant change	17	21	8	16
Pressure to change-economic, government, general management	6			2
Not sure change can be achieved	N %	M %	P %	J %
Not sure can be accomplished-good in theory, not in practice	17	21		13
Not sure key people are ready to change (charge nurse)	22		15	13
Turnover of staff too quick to achieve change	22			9
Not got the time		7		2
Should change - not sure ready	6			2

Table 62: continued

Needs someone else to suggest the change	N %	M %	P %	J %
You suggest the change and we will try it	11			4
Not sure can do it on own - need someone to suggest things	6			2
Miscellaneous	**N %**	**M %**	**P %**	**J %**
As ready as it ever will be		7		2
Surprised consultant willing to change		7		2
Some people will always resist change		7		2
Doesn't need change anymore than any other ward			8	2
Staffing levels are good for change to occur	6			2

Table 63: Initial Interview: Difficulties changing practice

Lack of time - requires more effort	N %	M %	P %	J %
Take more time - insufficient time	33	36	38	36
Initially more demanding - not run smoothly		7	15	7
Can do too much and get nowhere	6	14		7
Pressure of other work commitments e.g. acute sick	6	7	8	7
Requires conscious effort to think differently		7	8	4
Difficult to keep to timetables		7		2
Can't quickly change behaviour			8	2
Only able to give superficial care			8	2
Staff transiency	**N %**	**M %**	**P %**	**J %**
Staff move round so much - may not co-operate	33	29	38	33
Shift patterns - hard to communicate			31	9
New staff might not agree	6			2
Reluctance to change	**N %**	**M %**	**P %**	**J %**
People may be set in their ways	50	7	8	24
No enthusiasm for change in practice	22	29	8	20
Staff not sure where changes will lead to - need to see results	11	21	8	13
Can't change routine to suit relatives		14	8	7
Resistance to change - antagonistic			15	4
Depends how changes fit in - ?beneficial			8	2
Charge nurse reluctant to change - not her idea	6			2
Frightened to initiate change - labelled trouble maker	6			2
Lack of leadership and organisation	**N %**	**M %**	**P %**	**J %**
Charge nurse key figure - not committed to change	22	21		16
Needs leadership and monitoring	11			4
May not be supported by management	11			4
Depends on leader and boss		7		2

Table 63: continued

Adjusting to different roles	N %	M %	P %	J %
Adjusting to different roles takes time	17	14	31	20
Radical change - not done before	28			11
Some medics won't see where LPC fits in	11	14		9
Reluctance of professionals to give up skills		7	8	4
Newly qualified staff lack skills	11			4
Charge nurse doesn't feel solely in charge - adjust to role change	11			4
Lay people may not want participation in care	N %	M %	P %	J %
Quality of support from family and patient - may not want it	11	21	15	16
Patients traditionally passive - may not want it	6	29	8	13
Difficult to persuade to become involved	6	7		4
Relatives may sabotage plan - not share goals	6		8	4
Relatives initially frightened		7		2
Hard to stop collusion - change behaviour			8	2
May not want to do dirty jobs - seen as nurses' role			8	2
May not want family to be involved			8	2
Lack of contact with relatives	N %	M %	P %	J %
Hard to contact relatives - visit in evenings	6	14	31	16
Visitor's working	6	14		7
Relatives live too far away - do not exist		14		4
Difficulties with communication in MDT	N %	M %	P %	J %
Hard to communicate in multidisciplinary team	22		23	16
Getting the changes known - protocol and procedures	6	14	15	11
Communication breakdown	17		15	11
Need to continually remind people		7	8	4
Everyone needs to be included e.g. cleaners			15	4
Nurses don't know what is happening on the ward		7		2
Lack of enthusiasm	N %	M %	P %	J %
Done half heartedly - poor repercussions	28		8	13
Inertia due to apathy -and different personalities	6	29	8	13
May not be prepared to put in own time - extra effort	28	7		13
Just seen as short term project			15	4
No impetus for change at nursing level		7		2
Keen at first - enthusiasm dwindle	6			2
Poor communication between professionals and lay people	N %	M %	P %	J %
Professionals not always best to talk to lay people	11	7	8	9
Difficult to convince relative don't have to come in		7		2
Some patients have language problems		7		2
May be misinterpreted by lay people	6			2

Table 63: continued

Inability to participate	**N %**	**M %**	**P %**	**J %**
Depends on intelligence - ability to take on complex issues	6	14	8	9
Some not capable - mentally or physically	6	14		7
Fear of legal implications	**N %**	**M %**	**P %**	**J %**
Legal implications	11		15	9
Lack of resources	**N %**	**M %**	**P %**	**J %**
Lack of finance - equipment not right	11		15	9
Lack of resources after discharge - need support			8	2
Insufficient staff to implement change	6			2
Inadequate training for LPC	**N %**	**M %**	**P %**	**J %**
Need to train staff who have been on other wards	17			7
Individual thought drummed out in training	6	7		4
Medical dominance	**N %**	**M %**	**P %**	**J %**
Medic's patriarchal attitude			2	
Cautious about change - responsible to consultant	11			4
Nurses lack confidence to argue for change		7		2
Medical team not agreeing			8	2
Miscellaneous	**N %**	**M %**	**P %**	**J %**
Personality clashes			15	4
Difficulty to practice what preach	11			4
Administrative difficulties		7		2
Not work in hospital setting unless relatives come in too		7		2
Not just dealing with on group of patients			8	2
Not feasible to have relatives around all the time			8	2
Relatives may feel inhibited			8	2
Not work in London teaching hospital - not priority	6			2
Lack of skills	**N %**	**M %**	**P %**	**J %**
Newly qualified staff lack skills	11			4
People in charge too junior - not capable		7		2
No difficulties			8	2

Table 64: Initial Interview: Particular patients benefit
M= Medical (14), P=Paramedics (13), N=Nurses (18), J=Joint (45)

Illness related	**N %**	**M %**	**P %**	**J %**
Strokes	**50**	**43**	23	**40**
Alcoholics and cirrhosis	**50**	**36**	**31**	**40**
AIDS and HIV	**44**	**29**	8	**29**
Long term chronic	6	**43**	15	20
CHD and MI	22	21	8	18
Chronic colitics	22	21		16
Terminally ill	11	**29**	8	16
Confused elderly	11	7	31	16
Asthmatics	17	14	8	13
Diabetics	11	21		11
Head injury-brain damaged	11		15	8
Chest patients	17		8	9
Cancer	11			4
Acutely ill		7		2
Hypertension		7		2
Arthritis		7		2
Stoma patients		7		2
Paediatrics			8	2
Gynaecology			8	2
Renal patients			8	2
Gastrointestinal surgery			8	2
Mentally ill - semi-dependent	6			2
Hiatus hernia	6			2
Oesophageal varices	6			2
Duodenal ulcer	6			2
Multiple sclerosis	6			2
Personal characteristics	**N %**	**M %**	**P %**	**J %**
Young	**28**	14	15	20
Elderly	6	7	**31**	13
Intelligent	6	21		9
Interested and co-operative	6	7		4
Foreigners	6	7	8	7
Will to live		7		2
Smoking	6			2
Everyone/most	17	7	23	16
Social characteristics	**N %**	**M %**	**P %**	**J %**
Social admissions - unable to cope at home	11	7		7
Supportive network	11			4

Table 64: continued

Need help with ADL	**N %**	**M %**	**P %**	**J %**
Inability to communicate			23	7
Going to toilet		7	8	4
Need help with eating and drinking		7	8	4
Mobility problems			15	4
Frail		14		4
Paralysed dependent		7		2
Need help with dressing			8	2
Miscellaneous	**N %**	**M %**	**P %**	**J %**
Bored - need stimulation		7		2
Those taking medication		7		2
Depends on individual		7		2
Know will be discharged			8	2
Getting better			8	2
Those shaken by hospitalisation			8	2

Table 65: Initial Interview: Particular patients not benefit

	N %	**M %**	**P %**	**J %**
Very few - none	**28**	21	23	24
Those with mental impairment	**N %**	**M %**	**P %**	**J %**
Demented and confused	6	21	15	13
Psychiatric - depressed		21		7
Liver failure and confused	17			7
Not mentally able		7		2
Those with social difficulties	**N %**	**M %**	**P %**	**J %**
No relatives	17	21		13
Anxious relatives	6	14	15	11
Don't get on with relatives	17			7
Live alone		14		4
Social admissions	11			4
Drop outs		1		2
Highly dependent	**N %**	**M %**	**P %**	**J %**
Not physically able	6	14		7
Heavily dependent	11			4
Unconscious		7		2

Table 65: continued

Disease related factors	**N %**	**M %**	**P %**	**J %**
HIV	17			7
Alcoholics		14		4
Multiple problems	11			4
Drug users		7		2
Spinal lesions			8	2
Cancer			8	2
Pancreatitis	6			2
Condition related factors	**N %**	**M %**	**P %**	**J %**
Very ill	6	14	31	16
Terminally ill	6	7	8	7
Acutely ill	6	7		4
Hospitalised for less than 10 days			15	4
Miscellaneous	**N %**	**M %**	**P %**	**J %**
Elderly		7	15	7
Unwilling and uncooperative	6	14		7
Foreigners	6	7		4
Long term ill- complicated complications		7		2
Unusual problems			8	2
Not asked		7		2
Pain - can't concentrate			8	2
Habits not want reinforcing			8	2

Table 66: Initial Interview: Personal experience of hospital care

Experience of self or other in hospital	**N %**	**M %**	**P %**	**J %**
Yes	**83**	**71**	**92**	**82**
No	17	**29**	8	18
Self	17	**29**	23	22
Family	**N %**	**M %**	**P %**	**J %**
Father	22	21	15	20
Mother	17	7	8	11
Grandfather	6		15	7
Aunt	11			4
Wife		7		2
Brother		7		2
Grandmother			8	2
Nephew		7		2
Cousin			8	2
Uncle	6			2
Friend	11	7	15	11

Table 66: continued

Other	N %	M %	P %	J %
Self help group			8	2
Child	6			2

Table 67: Initial Interview: Personal experience of lay participation in care in hospital

N=Nurses (18), M=Medics (14), P=Paramedics (13), J=Joint (45)

LPC not encouraged	N %	M %	P %	J %
Would have been more involved - but not asked	33	14	46	31
No participation		14	23	11
Not involved in decision making - wanted choice	6	7	15	9
Would have liked to do own haemoccults-less embarrassing	6			2
Not allowed access to notes	6			2
Hard for new people to be told by non professional	6			2
Nurses didn't approve of her laying him out	6			2
Lack of information - poor communication	**N %**	**M %**	**P %**	**J %**
Insufficient information on what to expect (cond, trtmt and prevt)	39	21	8	24
Poor communication		14	15	9
No one available to speak to	6	7	15	9
Questions blocked	17			7
Never approached by a professional		7	8	4
They had to initiate contact with medics	6		8	4
Nurses not aware of decisions		7		2
Whispered behind curtains	6			2
Experience different because health professional	**N %**	**M %**	**P %**	**J %**
Treated differently because member of health profession	6	36	15	18
Worse being a nurse - didn't feel in control	17			7
Initially hard for non-medic to get involved		7		2
Anxiety about being in hospital	**N %**	**M %**	**P %**	**J %**
Shocked, anxious, scared - mysterious monitors	22	14	15	18
Frightened to do something wrong	6	7	8	7
Enormous strain on family - deteriorating condition		7		2
Hospitalisation stressful		7		2
Felt frightened because no one explained			8	2

Table 67: continued

Didn't want to participate	**N %**	**M %**	**P %**	**J %**
Some areas where happy to be passive		36	15	16
Wouldn't want to be involved in personal care	17		8	9
Put confidence in professional care and medicine		14		4
Left to get on with own care - didn't like it		7	8	4
Felt it was professional's duty to care		7	8	4
Aspects of care wouldn't like e.g. needles and colostomies	11			4
Wouldn't want participation	11			4
Didn't want to do own observations		7		2
More anxious because having to monitor self		7		2
No need to be involved - short stay only	6			2
Made to feel inferior	**N %**	**M %**	**P %**	**J %**
Made to feel inferior - no respect shown	22		23	16
Embarrassed to ask for help	11			4
Felt inadequate		7		2
Felt didn't belong - isolated	**N %**	**M %**	**P %**	**J %**
Patient transiency - them and us	28		15	16
Felt like intruder - not know what to do - isolated	11	7	15	11
Different on other side of the fence		7	8	4
Felt neglected		7	8	4
Not sure what to get involved in			8	2
Not complain - fear of jeopardy	6			2
Nurses too busy to ask	6			2
Good communication - well informed	**N %**	**M %**	**P %**	**J %**
Well informed		14	15	9
More information given	6			2
Knew what services were available - not a burden	6			2
Ward routine dominated and task oriented	**N %**	**M %**	**P %**	**J %**
Routine and regimented	22			9
Kept waiting		7		2
Nursing care poor	**N %**	**M %**	**P %**	**J %**
Discharge self	17	7		9
Staff too busy to care properly - no extras	6		8	4
Not given drugs on time		7		2
Poor discharge - no services			8	2
Lack of services			8	2
Not sure who to talk to about financial difficulties			8	2
Protected patient from nurses rushing	6			2

Table 67: continued

Allowed to be involved in care	**N %**	**M %**	**P %**	**J %**
Involved in care - BP, urinalysis	6	14		7
Able to support emotionally				
Involved in care after discharge	6	7	8	7
Took in food			23	7
Helped with sitting up, dressing and toilet	17			7
Consulted throughout - understood illness	6	7		4
Took in clean clothes	6		8	4
Brought things in at visiting time	11			4
Involved in own drugs		7		2
Helped to make the beds			8	2
Involved in care - discussions before discharge			8	2
Allowed to question	6			2
Given choice	6			2
Picked things up as complications developed	6			2
Did everything except drugs	6			2
Helped with feeding	6			2
Psychological care not met	**N %**	**M %**	**P %**	**J %**
Impersonal care - no privacy	6		15	7
Welcoming atmosphere	**N %**	**M %**	**P %**	**J %**
Open, friendly, welcoming		7	8	4
Miscellaneous	**N %**	**M %**	**P %**	**J %**
Family widely interspersed			8	4
Care would improve if relatives involved			8	4
Complied when unwell - stopped when better		7		2
Nurses embarrassed to be watched	6			2
Restricted visiting	6			2
Want information to be given from medics	6			2
Organisation poor	6			2
GP good at explanation	6			2
Advised on smoking	6			2
Cared for when ill - self care when better	6			2
Open visiting	6			2
Supervised initially	6			2
Positive gains from involvement	**N %**	**M %**	**P %**	**J %**
Could cope emotionally with being involved	6			2
Felt doing something	6			2
Helped to feel part of the group	6			2
Good when hospitalised so long	6			2

APPENDIX XX

FINDINGS FROM EXIT INTERVIEWS

Introduction

This appendix contains tabulated summaries of the findings from the exit interviews. The aim of the exit interview was to ascertain health professionals' perceptions of lay participation in care, explore what change had occurred on the ward as a result of the project and to establish what difficulties had been encountered in attempting to introduce lay participation in care.

Interview transcripts were individually analysed for issues and points raised in relation to questions asked. Findings are described in terms of which issue and point was raised by which group of health professionals. Issues and points raised were then grouped into themes in order of importance based on the joint responses (medics, paramedics and nurses together). Those issues and points raised by more than 25% of participants in any one group have been highlighted in the tables. By giving such a detailed description of the findings in appendix it is hoped that the reader may be in a better position to judge validity of the conclusions drawn in the main thesis. By presenting the data in such detail it is intended that the descriptive statistics used should add a further dimension to, rather than detract from, the qualitative nature of the findings. In line with Miles and Huberman's (1984) approach to qualitative data analysis, the presentation of findings as descriptive tables should aid the reader to gain easy access to the data.

The descriptive tables will be presented under the headings of topics explored at interview. It should be noted that questions asked about lay participation in care did not differentiate between patients themselves and their family and friends getting more involved in care in hospital as this was thought to make the interview too cumbersome and was not thought to be important when looking at health professionals, attitudes to lay participation in care.

Table 68: Exit Interview: Professionals' Perceptions of LPC

N=Nurses (10), M=Medics (10), P=Paramedics (6), J=Joint (26)

Vague understanding of LPC (unfamiliar)	**N** %	**M** %	**P** %	**J** %
Patients and relatives involved in care	**50**	**90**	**50**	**65**
Not part of training - unprepared	**30**	10		15
Unclear what LPC is - intangible	20	**40**	17	27
Seen as a nursing issue		**50**	**33**	**27**
Not sure who wants to participate	20	**30**		19
Takes time to feel comfortable with ideas			17	4
Didn't realise how little patients understood about care			17	4
Some nurses angry if relatives didn't get involved	10			4
Involvement in practical care	**N** %	**M** %	**P** %	**J** %
Teach how to give treatments	20	**40**	**33**	**31**
Assist with activities of daily living	10	**60**		**27**
Take own drugs and supervise drugs		**30**	17	15
Take observations and monitor condition		10		4
Keeping lay people better informed	**N** %	**M** %	**P** %	**J** %
What is happening	20	**30**	**33**	**27**
What is wrong	10	**40**	17	23
More open and honest with patients	10	10		8
Familiar concept	**N** %	**M** %	**P** %	**J** %
Part of training and practice	10	20	**50**	23
Social expectation not to be passive	20			8

Table 68: continued

LPC seen as a cost effective measure	**N %**	**M %**	**P %**	**J %**
Help with nurse shortages	20	40		23
Suspicious of LPC - why being introduced		10		4
Fine line between self care and NHS cuts	10			4
LPC seen as a general approach to care	**N %**	**M %**	**P %**	**J %**
Help them to help themselves	40	10		19
Seen as part of the job	10	10		8
Different levels of participation		10		4
Quicker and better prepared for discharge	**N %**	**M %**	**P %**	**J %**
More input at home and confident	10	20	33	19
Improve recovery			17	4
Idealistic concept not practical	**N %**	**M %**	**P %**	**J %**
Difficult to practice in reality		20	33	15
Ideal striving to reach		20		8
Seen as extra work rather than an approach	10			4
Transiency of patients makes LPC difficult	10			4
LPC not socially expected	**N %**	**M %**	**P %**	**J %**
Expect professionals to do certain things	20	10	17	15
Not part of relatives' role to participate	20	20		15
Can make people feel guilty	30			12
Taking obs may be seen as encroaching on professional work		20		8
People may need to coaxing to be involved		10		4

Table 68: continued

Empowerment of lay people	**N** %	**M** %	**P** %	**J** %
Ask questions and have a say in decisions	20		17	12
Right to understand care given	10			4
Patients demand LPC - see notes	10			4
Professionals make decisions about care	**N** %	**M** %	**P** %	**J** %
Inform about decisions taken		**30**		12
Medics tend to decide treatments		20		8
Give advice		10		4
LPC should be selective (not for everyone)	**N** %	**M** %	**P** %	**J** %
Some patients not capable of involvement		10	17	8
Approached tentatively/selectively		20		8
Easier for young and more intelligent	20			8
Females less likely to get involved		10		4
Need to select appropriate people	10			4
LPC should be optional	**N** %	**M** %	**P** %	**J** %
Encourage people who want involvement	10		17	8
Inform/advice but allow choice	10	10		8
Needs to be individualised - not always wanted	20			8
Family wanted respite care	10			4
Some frightened to do things at home	10			4
Some relatives don't want to be intimate with patients	10			4
LPC - part of health promotion	**N** %	**M** %	**P** %	**J** %
Involved in general well being and health	10	10		8
LPC involves health education	10	10		8

Table 68: continued

LPC important concept for the future	**N %**	**M %**	**P %**	**J %**
Responsibility to improve are for future through LPC	20			8
Realise importance of LPC with experience		10		4
Lack of equality in lay professional relationship	**N %**	**M %**	**P %**	**J %**
Some things need to hide from patients			17	4
Need to learn to trust patients more	10			4
Need structured approach to introduce LPC	**N %**	**M %**	**P %**	**J %**
Can't introduce LPC without key nurse system	10			4
Benefit from a model to help put into practice	10			4

Table 69: Exit Interview: Changes on ward that are working/ good idea

N=Nurses (10), M=Medics (10), P=Paramedics (6), J=Joint (26)

More positive attitudes to LPC	**N %**	**M %**	**P %**	**J %**
Increased awareness of need for LPC	**50**	**80**	**50**	**62**
Putting people in touch with lay support groups	20			8
Discharges planned better - more lay involvement	10			4
More case conferences with lay people involved	10			4
Patients/relatives more involved - not asked to leave	10			4
LPC now being offered	10			4
Students copying staff and involving patients/relatives	10			4

Table 69; continued

Improved Multidisciplinary teamwork	**N %**	**M %**	**P %**	**J %**
Improved MDT communication	**60**	**30**	**100**	**58**
Weekly meetings - better informed/more thinking	**30**	20	**33**	**27**
Team pulling together more - better care	10	20	**33**	19
People know who to relate to in team better	**40**			15
Meetings good to discuss improvements in care			**33**	8
Staff more approachable	10	10		8
Nurses asking medics more about their patients		10		4
Know individual nurses' names			17	4
Meetings good in transient workforce	10			4
Medics more approachable	10			4
Orientation handbook for new staff good idea	10			4
Improved patient education	**N %**	**M %**	**P %**	**J %**
MRC introduced - better informed on drugs	**30**	**70**	**50**	**50**
Information leaflets - helpful/fun for patients	**40**	10	17	23
Better at teaching - health education	**40**	10		19
Information leaflets being used on ward		20	**33**	15
More skilled in health education	10			4
Patients better informed	10			4
Better communication with relatives/friends	**N %**	**M %**	**P %**	**J %**
Improved communication with relatives/patients	**60**	20	**50**	**42**
Patient letter good idea		20	**33**	15
Medics make themselves more available for patients/relatives	20			8
Better understanding of patients/relatives	**N %**	**M %**	**P %**	**J %**
Patients being seen holistically	**50**	10	33	**31**
Think about relatives more	**50**	10	17	**27**
Key nurse system - know patients in more detail	**30**	10	**50**	**27**

Table 69: continued

Key nurse system better way of organising care	N %	M %	P %	J %
Better relationships within nursing team	40			15
See patients more holistically	40			15
More aware of patients' needs/problems	20	10	17	15
Ward better organised	30			12
Good idea	30			12
Better able to get to know own patients	20			8
Better able to teach individual patients	20			8
Care planning improving	20			8
Patients care improving	10			4
Patients pleased to like to have named nurse	10			4
People accept the sense of using key nurse system	10			4
Better continuity of care			17	4
Discuss personal problems more	10			4
Enjoy being given own group of patients to care for	10			4
More positive atmosphere on the ward	**N %**	**M %**	**P %**	**J %**
Ward atmosphere improved	20	10		12
Better ward reputation	20			8
Students happier - like mentor system	10			4
Staff learning to be more flexible	10			4
Staff becoming more happy and relaxed	10			4

Table 70: Exit Interview: Changes not working

N=Nurses (10), M=Medics (10), P=Paramedics (6), J=Joint (26)

LPC not part of every day ward practice	N %	M %	P %	J %
Introduction of LPC floundering - too slow	30	100	33	58
Patient letter ignored - hard to initiate LPC	30	30		23

Table 70: continued

MRC system failing	**N %**	**M %**	**P %**	**J %**
System not working - not being carried out	20	60	33	38
Problems with MDT teamwork	**N %**	**M %**	**P %**	**J %**
Communication sheet not being used	10	30	67	31
Meetings too short to be effective as a team		20	33	15
Meetings not always attended	10	10	17	12
Meetings medically dominated		10	33	12
Some suggestions threatening to medical model			17	4
Key nurse system not working properly	**N %**	**M %**	**P %**	**J %**
Not carrying out key nurse roles	10	20	50	23
Not handing over patients properly	20			8
People not speaking directly to key nurses about patients	10	10		8
Only know about own patients not the whole ward	20			8
Not writing care plans properly	20			8
Not working as a team - only with own patients	10			4
Changing practice difficult/stressful	**N %**	**M %**	**P %**	**J %**
New systems of work difficult to adjust to	20			8
Ill prepared to act as co-ordinators	20			8
Not happy delegating work - prefer being in charge	10			4
Not happy with format of report	10			4
Worried changes will do more harm than good	10			4
Not feeling confident in new role	10			4
Senior staff feel as though thrown in at the deep end	10			4

Table 70: continued

Problems with teaching roles	N %	M %	P %	J %
Information leaflets given out but not followed up			17	4
Not educating/supporting students enough	10			4

Table 71: Exit Interview: Desired Changes not Made

N=Nurses (10), M=Medics (10), P=Paramedics (6), J=Joint (26)

Need for better leadership of change	N %	M %	P %	J %
Charge nurse to monitor more closely/direct change	10	30	17	19
Need to remind people to do it		20		8
Consultant needs to be more positive/directive		10	17	8
Ensure new staff are aware of roles/responsibilities	10			4
More LPC in practice	**N %**	**M %**	**P %**	**J %**
More education on treatments/drugs	10	10	33	15
More information available to patients			17	4
Case conferences involving lay people			17	4
More lay involvement in activities of daily living		10	17	8
Patients returning for education after discharge		20		8
Involve patients/relatives in decisions			17	4
More information available to patients			17	4
Better facilities/resources for LPC	**N %**	**M %**	**P %**	**J %**
Room to teach in	20	10	17	15
More support in the community			17	4
Open visiting times		10		4
Get staffing levels right		10		4
More teaching materials available	10			4

Table 71: continued

Reorganise work to facilitate LPC	**N %**	**M %**	**P %**	**J %**
Patient allocation to facilitate LPC	10	20		12
Give more individualised care			17	4
Integrate into daily work - not extra job		10		4
Establish better system of Primary Nursing	10			4
Introduce Orem's model of nursing	10			4
Change social expectations	**N %**	**M %**	**P %**	**J %**
Need to re-educate people to feel able to participate	10	10	17	12
Get more out of MDT meetings	**N %**	**M %**	**P %**	**J %**
Longer meetings to facilitate discussions			33	8
Ensure medics are not so dominating in meetings			17	4
Meetings more structured with an agenda		10		4
Meetings more flexible in starting times		10		4
Better MDT work	**N %**	**M %**	**P %**	**J %**
Improve MDT - who does what	10		17	8
Share lay discussions with MDT		10		4
Nurses on ward rounds		10		4
Everyone working harder together for LPC	10			4
Like to change medics attitudes	10			4
Introduce more health oriented initiatives	**N %**	**M %**	**P %**	**J %**
Introduce aromatherapy			17	4
Introduce more education/relaxation tapes			17	4
More health education initiatives		10		4

Table 71: continued

Introduce LPC more globally in hospital	**N %**	**M %**	**P %**	**J %**
Involve whole hospital		10		4
Introduce concepts in training		10		4
Need to sort out things beyond own control e.g. pharmacy	10			4
Ensure communication with patients/relatives is good	**N %**	**M %**	**P %**	**J %**
Don't delegate communication with lay to inexperienced		10		4
Nurses better able to educate patients/relatives	10			4
Tend to do things without explaining why	10			4
Miscellaneous	**N %**	**M %**	**P %**	**J %**
MRC immediately before discharge		10		4
Get staff involved in writing more student reports	10			4

Table 72: Exit Interview: Barriers to Change

N=Nurses (10), M=Medics (10), P=Paramedics (6), J=Joint (26)

Lack of time/energy for changing practice	**N %**	**M %**	**P %**	**J %**
Too busy with other tasks - low priority	**90**	**100**	**67**	**88**
Hard to cope with routine without taking on new ideas	10	**60**	**67**	**42**
Needs to move faster - see results	10	10	17	12
Meetings too short to move ideas on		10	17	8
Initially takes longer to teach lay people	10	10		8
Patient plans change - difficult to teach	10	10		8
Unstable work force	**N %**	**M %**	**P %**	**J %**
Transiency of staff - lack of continuity	**40**	**80**	**83**	**65**

Table 72: continued

Reluctance to change practice	**N %**	**M %**	**P %**	**J %**
Resistance to change	60	50	67	58
Takes time to change routines/patterns of work	30	50	33	38
People in a rut - been in post a long time	30	30	67	38
Apathy - too much trouble to change	40	30	33	35
Some staff more flexible to change than others	50	40		35
Initially suspicious of LPC	10	10		8
Constant brick wall to changes	10	10		8
Lack of suitable patients for LPC	**N %**	**M %**	**P %**	**J %**
Not all patients/relatives are able/available/willing	50	40	67	50
People don't want responsibility for own health	20	10	17	15
Not all patients co-operative - frustrating		10		4
Lack of management support for change	**N %**	**M %**	**P %**	**J %**
Lack of enthusiastic leadership	50	60	33	50
Hierarchy slows process of change - inhibits juniors	30	20	50	31
Apathy - nobody making them do it	30	10	17	19
Lack of leadership/monitoring/checking up	30	20	33	27
Nursing management could have given more support	10			4

Table 72: continued

First charge nurse poor change agent	N %	M %	P %	J %
Blocked change/LPC	80	20		38
Negative attitude destructive	30			12
Didn't like authority to be questioned	30	10		15
Just going to work to do a job	30			12
Couldn't see the good of changing proactive	30			12
Tendency not to consult staff	30			12
Didn't like patients to have more say in care	20			8
Had out mode attitude to nursing	20			8
Lack of initiative/suggestions/direction	20			8
Didn't like meetings to discuss issues	10			4
Didn't like aspects of job - management	20			8
Couldn't facilitate staff to solve problems	10			4
Didn't expect to lead change	10			4
Didn't organise care to facilitate LPC	10			4
Found it hard to motivate/control staff	10			4
Felt unsupported by staff/management	10			4
Felt under increasing pressure at work	10			4
Poor communicator	10			4
Unhappy with nursing changes/developments	10			4
Lack of direction/guidance for junior staff	**N %**	**M %**	**P %**	**J %**
Poor management - lack of handover/induction	10	30	33	23
Inadequate support for juniors from seniors	20	20	17	19
Inadequate guidance of house officers from seniors	20	30		19
Too much reliance on house officers to make changes	20			8

Table 72: continued

Lack of multidisciplinary teamwork	**N** %	**M** %	**P** %	**J** %
Professional skills not valued within the team	10	20	60	35
Whole team not pulling together	50	20	17	31
Difficult to get a consensus	30	20		19
Medics not interested - just want to do their job	20			8
Staff not mature enough to work through difficulties	10			4
LPC - Different way of practice	**N** %	**M** %	**P** %	**J** %
Professionals used to medical model - LPC new concept	10	40	50	31
Apathy - couldn't see benefits	30	20	50	31
Got stuck on medical aspects of care		20	17	12
Not easily identify what to do	20		17	12
Lack of knowledge -not sure how could develop LPC	10		17	8
Not life and death - low priority		10		4
Don't see teaching as part of role	10			4
Aromatherapy too threatening			17	4
All staff need to change attitudes even domestics	10			4
Medics saw patients teaching as a low priority task	10			4
Lack of skills/confidence to facilitate LPC	**N** %	**M** %	**P** %	**J** %
Lack of skills/confidence to facilitate LPC	40	20		23
Uncomfortable initiating LPC	20			8
Unsure about assessing patients for LPC	20			8
Need to change attitude towards teaching role	20			8
Need to recognise do have skills for LPC	10			4
Medics vary in attitudes/skills for LPC	10			4
Inadequately prepared for teaching role	10			4

Table 72: continued

Conservatism stifling change	**N %**	**M %**	**P %**	**J %**
Frustrating/dispiriting when new ideas rejected	20	10		12
Consultant slowing process - vetting leaflets	10	10		8
Red tape blocking ideas	20			8
Concern for legal aspects inhibiting	20			8
Awaiting permission from solicitors		10		4
Poor environment for change	**N %**	**M %**	**P %**	**J %**
Inefficient systems get in the way of change	20	30		19
Ward doing things in isolation within hospital		20	17	12
Lack of democratic atmosphere - not allowed ideas	20	10		12
Competing needs students v staff	30			12
Task oriented/ routine based practice	**N %**	**M %**	**P %**	**J %**
Medics don't see patients holistically - task oriented	10	40		19
MRC not part of routine - hard to remember		20		8
Key nurses not working in own areas	20			8
People not taking responsibility for individual patients			17	4
Lack of motivation to develop professional practice	**N %**	**M %**	**P %**	**J %**
Just coming to work to do a job and go home	30	10		15
Career more important than developing practice		20		8
Loosing interest in profession		10		4

Table 73: Exit Interview: Lack of involvement in project

N=Nurses (10), M=Medics (10), P=Paramedics (6), J=Joint (26)

Insufficient commitment to project	**N** %	**M** %	**P** %	**J** %
Not involved enough with research project	20	**50**	23	**31**
Seen as a nursing issue		20	17	12
Lack of motivation to change		10	17	8
Not everyone enthusiastic about the project	20			8
Didn't want to be involved in more work			17	4
Lack of MDT work	**N** %	**M** %	**P** %	**J** %
Don't feel part of ward team	20		**100**	**31**
Researcher/Cons dominated MDT meetings			**33**	8
Don't know what other team members are doing		20		8
Agree with ideas but don't do anything	10	10		8
Seemed to focus on medical issues e.g. MRC			17	4
Lack of time for involvement	**N** %	**M** %	**P** %	**J** %
Too busy to be more involved	20	20	**67**	**31**
Wanted to be involved - didn't feel able (guilty)	10		17	8
Insufficiently supported by management	**N** %	**M** %	**P** %	**J** %
charge nurse - needs to be more directive/stress importance	20	**30**	17	23
Lack of ownership of ideas	**N** %	**M** %	**P** %	**J** %
Seen as researcher's ideas	10	20	17	15
Miscellaneous	**N** %	**M** %	**P** %	**J** %
Need to keep going - recognise change is slow			17	4

Table 74: Exit Interview: Issues related to Medicine Reminder Card System

N=Nurses (10), M=Medics (10), P=Paramedics (6), J=Joint (26)

MRC not being carried out properly	**N %**	**M %**	**P %**	**J %**
MRC system not working	20	**70**	**33**	**42**
Not being filled out and given to patients	**30**	**30**	17	**27**
Not followed up in clinic	10	20	17	15
3 monthly pattern of house officers adjusting to MRC	10	**30**		15
Not given out in hospital - left to the last minute	10	10	17	12
Lack of explanation to patients about MRC	20	10		12
Transiency of house officers - poor continuity		20		8
MRC good at discharge - not before		20		8
Difficult to persuade Drs it is a priority	20			8
Surprised how long it has taken to get system working			17	4
Medics more aware of need for patient education	**N %**	**M %**	**P %**	**J %**
MRC improved medics awareness of drug education		**60**	**67**	**38**
Realise how little patients know about drugs	20	**30**		19
Didn't realise patients wouldn't know about treatments			17	4
Realise need for MRC - patients return to clinic ill		10		4
Positive attitudes towards MRC system	**N %**	**M %**	**P %**	**J %**
MRC - important and must continue	10	**80**	17	**38**
Positive feedback from patients on MRC	10	**60**	17	**31**
Serves as a prompt to patients		**30**	17	15
MRC good for when return to clinic	10	20		12
Good for complex regimes		10		4
Lack of time/priority	**N %**	**M %**	**P %**	**J %**
Too busy to give out forms	10	**30**		15
Medics/Pharmacists too busy to educate patients	20		17	12
Not part of routine work - low priority	20	10		12
Not enough opportunity taken to educate about drugs	20			8

Table 74: continued

Teaching not part of normal practice	N %	M %	P %	J %
Feel uncomfortable with ability to educate	10	10		8
Need to be reminded to do it	10	10		8
Not clear whose role it is to teach			17	4

Table 74: continued

MRC system not suitable for every one	N %	M %	P %	J %
Not everyone suited to MRC - confused		10		4
Patients don't seem to use them		10		4
Good for patients with reasonable eye sight	10			4
MRC work better with nurses involvement	**N %**	**M %**	**P %**	**J %**
Nurses should get more involved in drug education	20	20		15
Easier with key nurse system working	10			4
Miscellaneous	**N %**	**M %**	**P %**	**J %**
Opens professionals to question/criticism		20		8
MRC not being evaluated properly	10	10		8
Doesn't give patients more information			17	4

Table 75: Exit Interview: Patients involved in care

N=Nurses (10), M=Medics (10), P=Paramedics (6), J=Joint (26)

AIDS Patients	**N** %	**M** %	**P** %	**J** %
Well supported and willing for involvement	**50**	**40**	17	**38**
Patient felt better because of LPC	**30**	20	**33**	**27**
Would initiate involvement normally themselves	**40**	10	17	23
Assist with activities of daily living	**30**	10	17	19
Discuss/question care	10	10	17	12
Became more flexible - allowed partners to stay	20	10		12
Well informed - young, articulate	20	10		12
Became involved to protect from prejudice	20	10		12
Involved in treatments - IVs /NG tubes - young	10	20		12
Difficult - friends/relatives may not know diagnosis			17	4
Feel guilty nurses having to care for them	10			4
Scared to be involved but overcame fear	10			4
More support available for AIDS patients	10			4
Not many patients involved in care	**N** %	**M** %	**P** %	**J** %
None/not many that can recall being involved		10	**50**	15
Terminally ill	**N** %	**M** %	**P** %	**J** %
Assisted with activities of daily living	**30**	10		15
Can direct staff what to do via relative	10	10		8
Relative act as advocate for patient	10			4
Need to involve relatives - poor prognosis		10		4
Give treatments	10			4
Supported family giving care	10			4
Allowed family to evaluate care given	10			4
Wife just wanted to be with patient - not give care	10			4

Table 75: continued

Stroke	**N** %	**M** %	**P** %	**J** %
Family wanted respite care	10	10		8
Assisted with activities of daily living/monitoring care	20			8
Family needed emotional support for taking patient home		10		4
Involvement can seem like unending sentence		10		4
Provide telephone link after discharge	10			4
Chest Problem	**N** %	**M** %	**P** %	**J** %
Physiotherapist not always there to give treatment			17	4
Alcoholics	**N** %	**M** %	**P** %	**J** %
Hard to get compliance after discharge			17	4
Families happy to have respite care		10		4
Spoke to wife - happier to take patient home		10		4
General lay involvement	**N** %	**M** %	**P** %	**J** %
On ward round patients involved to limited extent		10		4
Tend to discuss prognoses		10		4
Tends to be with life threatening illnesses		10		4
Needs to be explained/offered	10			4
Don't think of LPC with minor illnesses	10			4
Foreigner	**N** %	**M** %	**P** %	**J** %
Foreign refugee - gave dietary advice	10			4

Table 76: Exit Interview: Comments on research

N=Nurses (10), M=Medics (10), P=Paramedics (6), J=Joint (26)

Positive feelings towards researcher's input	**N %**	**M %**	**P %**	**J %**
Enthusiasm needed/acts as catalyst/stimulating	**40**	**40**		**31**
Researcher gave new insights	**30**			12
Need to include researcher's views in report		10		4
Used researcher for support	10			4
People didn't want to disappoint the researcher	10			4
Better if researcher had been charge nurse % onward	10			4
Researcher input at reports valued - changed thinking	10			4
Hierarchy support research	10			4
Project viewed positively	**N %**	**M %**	**P %**	**J %**
Ward practice slowly changing	20	20	17	19
Project ideas good - wanted them to work	**50**			19
Changed attitudes to work - stimulating	20			8
Established a talking culture - better relations	20			8
Became more aware of community resources	20			8
Helped people to re-examine their roles	20			8
Everybody gained something from research	10			4
Changes in line with future practice - good ideas	10			4
Helpful to discuss issues - put things in perspective	10			4
Better to have taken more focused approach	**N %**	**M %**	**P %**	**J %**
Select patients rather than take general approach	10	20	17	15
Better to evaluate more closely individual's work			17	4
Need to identify positive people - focus on them			17	4
Useful to look at differences in house officers		10		4

Table 76: continued

First charge nurse resented research	N %	M %	P %	J %
Felt criticised - threatened by research	50			19
Saw it as an intrusion on her ward	40			15
Initially wanted project but changed mind	40			15
Research made her feel she was loosing control	40			15
Took up too much time	40			15
Wanted research to fail	20			8
Regretted having project on the ward	20			8
Refused to be involved	20			8
Found project an extra pressure	20			8
Not research minded	20			8
Research brought problems into open - conflict	20			8
Staff went to researcher with problems - resented	10			4
Felt too much depended on her to change	10			4
Felt confused as to who the leader was	10			4
Found researcher too enthusiastic	10			4
Felt researcher needed a more subtle approach	10			4
Resented meetings - interrupted patient care	10			4
Didn't feel the need to change ward practice	10			4
Felt project was too time consuming	10			4
Felt whole ward was turned upside down	10			4
Felt unsupported in her views	10			4
Research alienated charge nurse from staff	10			4

Table 76: continued

Wrong environment for research	**N** %	**M** %	**P** %	**J** %
People too career oriented/apathetic to change	20	20		15
Better with more dynamic people/leader	30			12
Medics cynical about project - too negative	20			8
Better to start on fresh/different ward			17	4
Difficult to change practice with transiency		10		4
Can't rely on researcher - has to come from charge nurse		10		4
Not sure right time to do research	10			4
Uncomfortable - charge nurse not positive	10			4
Initially ward seen to be right for research - CNM	10			4
Charge nurse found it hard to motivate people	10			4
Ward stuck in old fashioned ways	10			4
Lack of ownership of project ideas	**N** %	**M** %	**P** %	**J** %
Project for researcher - low priority		10		4
Initiative comes from researcher - inadequate		10		4
People felt too much was expected of them	10			4
charge nurse % didn't understand aims/what expected	10			4
Different philosophical understandings of research	**N** %	**M** %	**P** %	**J** %
Difficult to measure something so abstract		10		4
Initially put off research because sociological		10		4
Need for a randomised control trial		10		4
Should sort out problems before starting		10		4
Need to persuade people of advantages			17	4
Decide aims before start - not well defined		10		4
Staff needed spoon feeding/guidance	10			4

Table 76: continued

Difficult type of research to do	**N** %	**M** %	**P** %	**J** %
Researcher had a lot of patience	10	10	17	12
Hard job for researcher - no power		10		4
Need to explain at beginning change will be slow	10			4
Research took more time than expected	10			4
Miscellaneous	**N** %	**M** %	**P** %	**J** %
Should involve students more	20			8
Questionnaire hard to complete			17	4
Change dependent on researchers presence			17	4
New staff need to be spoken to about research	10			4
Would have liked more input from researcher	20			8
Key nursing emphasised too much	10			4
Better if had been done on two wards	10			4

Table 77: Exit Interview: Environmental issues

N=Nurses (10), M=Medics (10), P=Paramedics (6), J=Joint (26)

Lack of staff/resources	**N** %	**M** %	**P** %	**J** %
Lack of staff to cover the wards	**50**	**30**	**67**	**46**
Difficult to recruit /retain staff in London	20	10	17	15
Financial crisis - cutbacks/wards closing		**30**		12
Work load iniquitous - staffing levels vary		10	17	8
System stretched - people only just coping		20		8
Inadequate facilities - lifts/food		20		8
Constant hassle to get things done		10		4
Rely on agency staff			17	4

Table 77: continued

LPC not professionally initiated	**N %**	**M %**	**P %**	**J %**
LPC - tendency to be lay initiated	**40**	**40**	**33**	**38**
Nurses fear giving information - refer to others	10	10		8
Take opportunity as it arises to talk to relatives	10			4
Not trained to think about LPC	10			4
Change imposed from above	**N %**	**M %**	**P %**	**J %**
Medics without power to stop hospital changes	10	**50**		23
Time of change - uncertainty local/national		**40**		15
Uncertainty of government proposals		**30**		12
Great deal of change - not all for the better		20		8
Nature of future work uncertain		20		8
Regrading added stresses	20			8
Audit being imposed on medics		10		4
Change being imposed from above	10			4
Work demands increasing	**N %**	**M %**	**P %**	**J %**
Hospital busier since hospital closure	10	**60**		**27**
No time to attend meetings - feel don't belong	10	10	**50**	19
Waiting lists increasing	10	**30**		15
Pressure on beds - poor administration		**40**		15
Every body's job is busier/harder	20	**30**		19
Work long hours		10		4

Table 77: continued

Unsupportive work environment	**N** %	**M** %	**P** %	**J** %
Charge nurse blocked energies/enthusiasm	**50**			19
Junior staff not valued/supported	10	20	17	15
Lack of professional development	20			8
S/Ns working hard despite constraints	20			8
Lack of supervision of work			17	4
Feel vulnerable- protect self with doing tasks		10		4
Lack of continuing education - students know more	10			4
Standards of care poor	**N** %	**M** %	**P** %	**J** %
Can't do job as well as would like/capable		20	**33**	15
Students not putting into practice what taught	**30**			12
Seen to be badly run ward	10	10	17	12
Lack of continuity of care		10	17	8
Sense of injustice due to poor patient care	20			8
Medics not interested in changing ward practice	**N** %	**M** %	**P** %	**J** %
Medics too powerful - hard to engage with		10	**33**	12
Medics not interested in what nurses do - patronising	**30**			12
Consultant can't be seen as change agent		20		8
Medics inadequately prepared to do basic job		20		8
Medics not co-operating with new ideas	20			8
Medics socialised not to ask q uestions/do tasks		10		4
Low morale	**N** %	**M** %	**P** %	**J** %
Morale low in NHS		**30**		12
Medicine less socially desirable as a career		20		8
Cut backs pose a threat to specialist research		10		4

Table 78: Exit Interview: Post script data

N=Nurses (10), M=Medics (10), P=Paramedics (6), J=Joint (26)

Qualitative difference in new charge nurse	**N %**	**M %**	**P %**	**J %**
Better able to motivate staff - enjoy work more	**90**			**35**
More enthusiastic/interested	**50**	**30**		**31**
More interested in developing practice	**50**	**30**		**31**
Creates a better atmosphere/team spirit	**50**	**30**		**31**
More open to changing practice/adopt others ideas	**70**			**27**
Creative/proactive - uses initiative	**40**	20		23
Sees patients more holistically	20	**30**		19
Ward better organised - less chaotic/calmer	**30**	20		19
More interested in staff development	**50**			19
More supportive/caring in relationships	**50**			19
More contact with - better relations	**30**	20		19
Wants to teach students/better supported	20	20		15
More knowledgeable of professional nursing issues	**40**			15
Better leader - more respected/role model	**40**			15
Qualitative difference in new charge nurse continued	**N %**	**M %**	**P %**	**J %**
Draws on staff's personal strengths	**30**			12
General morale and confidence higher	**30**			12
Delegates responsibility	20			8
Keeps staff better informed	20			8
More knowledgeable/analytical	20			8
More assertive with medics	10			4
Monitors work done in supportive manner	10			4

Table 78: continued

Positive changes under new leadership	**N** %	**M** %	**P** %	**J** %
Retraining staff to think more positively	30			12
Making systems work - MRC/key nursing	30			12
Better able to offer LPC	20			8
Work as an intermediate for patients between professionals	20			8
Care improved	20			8
Created a talking culture - express opinions	20			8
More able to teach	10			4
Enjoy responsibility of looking after own patients	10			4
Students happier - more relaxed	10			4
Difficulties encountered in changing leadership	**N** %	**M** %	**P** %	**J** %
Staff conflict - resistant to change/power battles	30			12
Changeover of charge nurse % difficult - project lapsed	20			8
Don't like having to do paperwork	20			8
Ward busy/staff tired/ too much to change	20			8
Staff struggling to take on new roles	20			8
Difficult to become facilitators/co-ordinators	20			8
Need to be more assertive	10			4
Need to be more supportive of colleagues	10			4
Monitor things being done properly	10			4

APPENDIX XXI

INTERVIEWS - SENIOR NURSE MANAGERS (DISTRICT NURSING)

Introduction

This appendix contains tabulated summaries of the findings from the interviews with Senior Nurse Managers (District Nursing). These interviews took place, at the suggestion of one of the participants, during the course of the research. It was suggested that District Nurses should be informed about the innovation on the ward and that they might have something interesting to say on the topic of lay participation in care. Senior Nurse Managers (District Nursing) were chosen as they would be best placed to disseminate information about the project and as there was limited time available to conduct the interviews with larger numbers of people. The aim of these interviews was to ascertain their understanding of lay participation in care, identify what changes would encourage lay participation in care and to establish what difficulties might be encountered when changing nursing practice.

Interview transcripts were individually analysed for issues and points raised in relation to questions asked. Those issues and points raised by more than 50% of participants have been highlighted in the tables. By giving such a detailed description of the findings in appendix it is hoped that the reader may be in a better position to judge validity of the conclusions drawn in the main thesis. By presenting the data in such detail it is intended that the descriptive statistics used should add a further dimension to, rather than detract from, the qualitative nature of the findings. In line with Miles and Huberman's (1984) approach to qualitative data analysis, the presentation of findings as descriptive tables should aid the reader to gain easy access to the data.

The descriptive tables will be presented under the headings of topics explored at interview. It should be noted that questions asked about lay participation in care did not differentiate between patients themselves and their family and friends getting more involved in care in hospital as this was thought to make the interview too cumbersome and was not thought to be important when looking at health professionals, attitudes to lay participation in care.

Table79: Perceptions of Lay Participation in Care

LPC - part of DN philosophy and practice	**Total**
Fundamental to DN	**87.5% (n=7)**
Important for nurses to develop educative and supportive roles	**87.5% (n=7)**
Nurses need to be re-educated into LPC	
Requires a new way of thinking - takes time	**62.5% (n=5)**
Nurses inadequately prepared for LPC - lack skills	12 5% (n=1)
May be seen as a threat - nurses need to learn to pass on skills	12.5% (n=1)
Lay people should be empowered more in hospital	
People should take their rights into hospital	**50% (n=4)**
Need to explore with pts where at, where going, set goals together	25% (n=2)
Teach people to have confidence to do it themselves	25% (n=2)
Time people took more responsibility for own health	25% (n=2)
Anything can be passed on to lay people	25% (n=2)
Need to support lay people in their care - not interfere	12.5% (n=1)
Need to help community to help itself	12.5% (n=1)
Need to demystify hospitals	12.5% (n=1)
Place for LPC even when total care is given by professionals	12.5% (n=1)
Ideal concept - hard to practice	
Idealistic and essential - but question if realistic	37.5% (n=3)
Enormous task to initiate in hospital	12.5% (n=1)
LPC is about health education and health promotion	
DNs involved in health education	25% (n=2)

Table 79: continued

LPC should be optional - not forced	
Should not expect people to be involved	12.5% (n=1)
Can't change people's lifestyles - only advise	12.5% (n=1)
Lay people can't do certain things	
Change drips	12.5% (n=1)
Do wound dressings (why have training)	12.5% (n=1)
Not medications (then changed mind!)	12.5% (n=1)
Miscellaneous	
GPs changing attitudes eventually consultants will	25% (n=2)
Lay and professional need to work together (can't manage without) - lead way	25% (n=2)
LPC and gender - appear women happier to care	12.5% (n=1)
Gay want to help themselves - not judged by society	12.5% (n=1)
Access to money and support - need to consider needs for other illnesses	12.5% (n=1)
Support family giving care - not interfere	12.5% (n=1)
Offer supportive relationship - contact with professional services	12.5% (n=1)

Table 80: Specific patients - benefit from being involved in care

AIDS	**75% (n=6)**
Elderly	**50% (n=4)**
Terminal illness	37.5% (n=3)
Articulate - able to communicate with professionals	37.5% (n=3)
Living alone - sometimes no family (would benefit from LPC)	25% (n=2)
Isolated in society - aware of and confront rights and choices	25% (n=2)
Other conditions	
Paediatrics - done for a number of years	12.5% (n=1)
Renal dialysis - relatives there by right	12.5% (n=1)
Arthritis	12.5% (n=1)
Diabetes	12.5% (n=1)
Colostomy	12.5% (n=1)
Early discharges - need someone with finger on pulse	12.5% (n=1)

Table 81: Lay participation in care - advantages

Advantages - lay people	
Gives people more freedom (not wait for DN)	25% (n=2)
Makes people feel more knowledgeable and confident	12.5% (n=1)
People want to be independent	12.5% (n=1)
Everybody informed - no secrets and share burden	12.5% (n=1)
Better care on discharge	12.5% (n=1)
Advantages - professionals	
Makes the job of district nursing easier	37.5% (n=3)
Health professionals learn from dealing with taboo subjects - death, sexuality	25% (n=2)

Table 82: Lay participation in care - disadvantages

Relatives may not be able and/or capable to take on care	
May not fit in with own lives - (too busy, other responsibilities, burden)	**87.5% (n=7)**
Not capable - age, disability, illness, intellect	**50% (n=4)**
Relatives not local or do not exist	**50% (n=4)**
May not want to take long term commitment on	12.5% (n=1)
Relatives may not want to take on care	
Relatives may be frightened of taking on care - something go wrong	**62.5% (n=5)**
May not want to get involved in care	**50% (n=4)**
Individuals may be embarrassed at doing intimate things	**50% (n=4)**
See hospitalisation as respite care	12.5% (n=1)
Unemployed do not want to take on voluntary work	12.5% (n=1)
Relatives may not see it as their role	
May see it as professionals off loading their work	37.5% (n=3)
Young may not see LPC as their responsibility	12.5% (n=1)

Table 82: continued

Patient may not want it	
May be friction in the family - not want person	25% (n=2)
Enjoy the sick role - like being dependent on services	12.5% (n=1)
May be worried about confidentiality	12.5% (n=1)
LPC may lead to harm	
May build up wrong expectations prior to discharge	12.5% (n=1)
Relatives may feel guilty if withdraw	12.5% (n=1)
May lead to hypochondria	12.5% (n=1)
Relative may become exhausted caring	12.5% (n=1)
Disadvantages for health professionals	
Relatives could get in the way of a busy ward	12.5% (n=1)
Time consuming	12.5% (n=1)
Stopped from doing it - staff shortages	12.5% (n=1)

Table 83: Specific patients - not benefit from being involved in care

Surgical	12.5% (n=1)

Table 84: Constraints introducing LPC

LPC not work in hospital	
Staff routines and attitudes not support LPC	25% (n=2)
People made to feel vulnerable in hospital	12.5% (n=1)
Still not meeting basic needs without LPC	12.5% (n=1)

Table 85: Personal experience of LPC

Husband in hospital - cancer	12.5% (n=1)
- husband not seen as an individual	
- wanted to give care (neglected by nurses)	
- felt care could have been better	
- nurses concentrated on technical aspects of care	
- nurses never asked how she was	
- other visitors more helpful than the nurses	
- all contact with professionals was initiated by her	
- professionals not working as a team	
- nurses referred her to doctors for information	
- doctors helpful at giving information	
- ward very busy (staff juggling priorities)	
- felt was helping ward staff	
- felt scared of equipment	
- frightened of doing something wrong	
- frightened of what going to hear	
- didn't want to offend anyone	
- visitors questions appeared threatening	
- visitors made to feel in the way	
- relatives didn't know what was happening	
- wanted more support	
- patient content with care	

Table 86: Suggestions for Change

Need to view patient in context of family	
Need to assess motivation to care or not care	**62.5% (n=5)**
Need to be aware of whole family and friends - friction amongst relations	**50% (n=4)**
All friends and relatives interviewed (explore relations and explain things)	**50% (n=4)**
Need to follow up relatives for feedback	12.5% (n=1)
Establish teaching plan with family	12.5% (n=1)

Table 86: continued

Nurses need to develop skills for LPC	
Counselling skills - adjust to illness and discuss fears (takes time)	**50% (n=4)**
Need to supervise and assess competence	37.5% (n=3)
Concepts need to be taught - how to teach	25% (n=2)
Nurses need to have surveillance role	12.5% (n=1)
Patient involved in care planning	
Involve patient in discussions	37.5% (n=3)
Explore where at, where going, set goals	37.5% (n=3)
Patients should choose what carers do	12.5% (n=1)
Need good liaison between hospital and community	
Need to establish network of support in the community	37.5% (n=3)
Involve DNs in ward decisions about discharge	37.5% (n=3)
Nurses should work in and out of hospital (better understanding)	25% (n=2)
Ensure good links between GP and hospital	12.5% (n=1)
Need to discuss discharge with all those involved	12.5% (n=1)
Need to change social expectations	
Re-educate lay people to participate in care	37.5% (n=3)
Sensitively introduce idea in hospital - explicit philosophy	12.5% (n=1)
LPC needs to be planned and well organised	
Prepare for LPC immediately on admission	37.5% (n=3)
Need commitment from the top	25% (n=2)
Need designated nurse to ensure continuity	12.5% (n=1)
Firm leadership - specific roles and responsibilities	12.5% (n=1)
Nurses would need support themselves - adjusting to illness and death	12.5% (n=1)
Need to have key co-ordinator in family to relate to	12.5% (n=1)

Table 86: continued

Need to be aware of the stress and strain placed on carers	
Practice caring at home before discharge (home visits)	37.5% (n=3)
Understand the need for respite care	25% (n=2)
Preparation for carer's role should be gentle	25% (n=2)
All carers should be paid	12.5% (n=1)
Not show displeasure if not wanting involvement	12.5% (n=1)
Involve in practical aspects of care	
Diabetic	25% (n=2)
Rehabilitation	12.5% (n=1)
Instil eye drops and ointment	12.5% (n=1)
Give basic care	12.5% (n=1)
Assist with activities of daily living	12.5% (n=1)
Colostomy care	12.5% (n=1)
LPC needs facilities , resources and proper environment	
Need to lift restrictions in hospitals - televisions, use of side wards, visiting	25% (n=2)
Need privacy for discussion	12.5% (n=1)
Services need to be flexible	12.5% (n=1)
Special discharge ward to teach people	12.5% (n=1)
Ensure people discharged with adequate supplies	12.5% (n=1)
Get rid of nursing jargon	12.5% (n=1)
Need good multidisciplinary team work	
Generic nurse better	12.5% (n=1)
Establish teaching plan with district nurses	12.5% (n=1)
Need to appreciate and value long term goals within the team	12.5% (n=1)

Table 87: Environmental Issues

Nursing accepting LPC in theory	
Nursing going in the right direction - professionally held concepts	**75% (n=6)**
Patients discharged with unrealistic expectations of care	
Discharged expecting services can't have (no resources)	**62.5% (n=5)**
Patients believe hospital promises of care and support in community	37.5% (n=3)
LPC not socially accepted as normal practice	
Patients expect to be passive	**50% (n=4)**
As move to private practice - lay will demand more involvement	12.5% (n=1)
Long term disabled expect services by right	12.5% (n=1)
In past people never had things explained	12.5% (n=1)
LPC - not part of professional practice	
Nurses not good at involving patients	37.5% (n=3)
Years of tradition to be broken down	37.5% (n=3)
Nurses cling onto traditional nursing tasks - aseptic technique	37.5% (n=3)
Hospitals encourage dependency	25% (n=2)
Medical views would need to be challenged	12.5% (n=1)
Nurses feel more comfortable in control of care	12.5% (n=1)
LPC - viewed as a cost effective and efficiency measure	
Fits in with government policy - people responsible for own health	37.5% (n=3)
Needed - soon not enough qualified nurses	25% (n=2)
Some might accept concept more in better economical climate	12.5% (n=1)
LPC needed - insufficient finance for support in community	12.5% (n=1)

Table 87: continued

LPC fits in with DN approaches to care	
Makes DN job easier if started in hospital	37.5% (n=3)
LPC would free up district nurses to do more preventive work	12.5% (n=1)
Confusion of roles in the community	
Confusion as to who is doing what in the community	37.5% (n=3)
Improving - becoming more aware of roles	12.5% (n=1)
Communication networks invaluable to organise care	12.5% (n=1)
Community complex - many different people to contact	12.5% (n=1)
Care in the community different to care in hospitals	
Professional has less control over clients in community	37.5% (n=3)
LPC helps people not to adopt sick role in hospital	12.5% (n=1)
Hospital students find community an enlightening experience	12.5% (n=1)
Better teamwork in the community - know pts well	12.5% (n=1)
Geriatric units have better understanding of community	12.5% (n=1)
Hospitals don't allow for homely environment - not patient-centred	12.5% (n=1)
Hospitals don't always appreciate nature and value of community work	12.5% (n=1)
Community nurses need to get rid of hospital thinking	12.5% (n=1)
Community workers need to be less judgmental	12.5% (n=1)
Hospital nurses more technical	12.5% (n=1)

Table 87: continued

Community not coping with current workload	
Carers already complaining of isolation and lack of support	25% (n=2)
Short of staff at weekends	25% (n=2)
District nurses couldn't manage without help of other agencies (voluntary)	25% (n=2)
Inundated in community with people needing care	25% (n=2)
Lay organisations - couldn't manage without, do a better job	25% (n=2)
Home helps not meeting demands	12.5% (n=1)
Things tend to be left to district nurses to pick up	12.5% (n=1)
Case loads need to be reassessed	12.5% (n=1)
Voluntary services closing - lack of funds	12.5% (n=1)
LPC needed - present system inadequate	
Patients are discharged not understanding their medication	12.5% (n=1)
Nurses not good at psycho social aspects of care	12.5% (n=1)
Part of quality assurance	12.5% (n=1)
Professionals have a lot to learn from lay organisations	12.5% (n=1)
Inappropriate discharges	12.5% (n=1)
Ageing society - more people to care for at home	12.5% (n=1)
Nurses too busy to teach	12.5% (n=1)
Problems recruiting staff	12.5% (n=1)
Miscellaneous	
LPC and gender - appear women happier to care	12.5% (n=1)

APPENDIX XXII

SUMMARY OF FINDINGS FROM FIELD NOTES

Introduction

Throughout the study daily field notes were recorded. These field notes were systematically analysed for issues relevant to the professionals' perceptions of lay participation in care, the change process itself and on the process of doing the research. Initially these issues were noted in a margin at the side of the 834 pages of hand written field notes (A4 size). On account of being an active participant in an action research study that had encountered many stressful events there was felt to be a need to take into account the process of doing the research. For this reason the analysis of the field notes began by examining the feelings engendered in the researcher during the study. A note was made of the month, page number (for ease of cross reference) and whether the issue raised was seen as inducing positive or negative feelings in the researcher. In this way issues could be systematically traced back to their original source for confirmation and the feelings engendered in the process of doing the research explored over time. These issues and problems were then analysed per month and grouped under themes. It was therefore possible to examine the emergence of feelings and themes over time. These data concerned with the process of doing the research are addressed in more detail in the self reflective enquiry chapter (Chapter 10). Many comments did not induce particularly strong feelings and were therefore labelled as "interesting". Having traced the engendered feelings in the research process, the significant events which occurred during the study were highlighted and these data formed the basis of the first chapter of the thesis which told the story (Chapter 1). Finally the issues raised (positive, negative and interesting) were grouped together and analysed for emerging themes. These themes are described below:

WARD PRACTICE NOT CONDUCIVE TO CHANGE

Staff set in task oriented approach not professional model

- find it hard to break old habits (running two systems of care)
- need guidance and support to develop confidence in new roles
- find it hard to work in a democratic way as equal partners
- feel over loaded - not coping with job (disorganised)
- quick to complain but slow to take action when given opportunity
- find it hard to adjust to not knowing all patients, yet knowing a few patients well
- new staff better able to offer partnership in care

- staff set in old routines and habits (?easier to start with new team)
- staff recognise need to change thinking and practice (roles changing - holism)
- old C/N takes a functional approach to work rather than developmental
- house officer's job routine and task oriented (hide behind tasks and not think)
- old C/N felt out of control when ward practice was challenged
- consultant recognises difficulty in getting medics to change
- difficult to make change (want to see it work first)
- house officers seen a clerks to gather information for consultant
- MRC system not working because not part of a routine
- work oriented to meet professional needs not patient needs
- partner complained care given as being fragmented not holistic
- staff just coming to work to do a job (not willing to make extra effort)
- house officers motivated by own career (get jobs done to please consultant not patients)
- old C/N not interested in professional development
- key nurse system not working (not organised and led properly)
- S/Ns resisting decentralisation of care
- new C/N finding development work daunting and demanding - takes time and effort
- change slow - very demanding (takes up personal time and energy - exhausting)

Transiency - no stable workforce to develop change

- constant flux of new people requiring orientation - need handout
- hard to make change with changing workforce
- transiency affects continuity of innovation
- staff not immediately replaced
- difficult to stay on top of data collection with constant staff changes
- ward unsettled when staff change
- MRC not working - takes 3 months to establish commitment and then go
- care fragmented due to lack of continuity
- lack of multidisciplinary teamwork- poor communication
- easier to do things oneself than keep on re-educating others
- house officer's transiency leads to lack of continuity
- senior medic unwinding and withdrawing from ward (new job)
- hard to form relationships due to staff changes

Lack of enthusiastic support for change from key leaders

- old C/N and consultant's lack of enthusiasm for suggested changes (expect failure)
- meetings cancelled by old C/N (too time consuming, mind on ward)
- motivation to participate in new ideas comes from researcher not old C/N
- sense of apathy (research expressed as a low priority)

- negative attitudes dampen enthusiasm
- frustration at attempts to change being blocked
- old C/N and consultant not maintaining new systems of work (essential for innovation)
- participants lack sense of achievement (disillusioned)
- staff turn to researcher for leadership (old C/N not leading initiatives)
- lack of creative ideas (no suggestions when S/Ns have problems)
- lack of role model and no professional guidance (want researcher to be leader of ward)
- old C/N not have leadership qualities to support change
- old C/N shows negative attitude to family involvement
- S/Ns identify the need for an enthusiastic leader to develop and facilitate LPC
- old C/N fed up with nagging S/Ns to do things (demotivating)
- old C/N not like role in maintaining team cohesion
- old C/N giving mixed messages (one minute supports and then disapproves)
- lack of enthusiasm seen as a major barrier to change
- ward not ready for change (not motivated)

Lack of team work - no participation amongst professionals (medical dominance)
- consultant and medical domination of meetings and decisions (not challenged)
- lack of input from paramedics and junior medics (pay lip service)
- no one challenges medical conservatism
- old C/N not want to change things in case trouble with medics
- S/Ns not want to change things in case trouble with old C/N
- different people working different systems of care
- poor communication within multidisciplinary team - poor relationships
- inter staff conflict - take criticism personally
- transiency makes relationships difficult
- medical dominance (make changes without consulting team)
- researcher made to feel inferior by consultant
- lack of medical involvement with ward
- lack of medical management and development (new C/N main change agent)
- new house officers assert themselves in meetings when consultant not there
- new C/N conscious of subservient role imposed on her by medics
- takes time and assertiveness to be respected by medics
- leaflets in consultant's room not being used (lack of collaboration)
- medical dominance due to lack of nursing leadership
- not all people are enthusiastic (hard to motivate to work together)
- need full team co-operation or enthusiasm runs out
- medics not appreciating changes being made in professional nursing

Poor ward organisation and management to facilitate change
- key nurse system to facilitate LPC not working properly
- old C/N doesn't value extra information being given in report
- LPC meetings have low priority (not always well attended)
- MRC system not working (house officers uncommitted to roles and responsibilities)
- nurses not taking action when know patient is unhappy to be discharged
- LPC haphazard and not planned (needs to be introduced purposefully)
- too much off loaded onto house officers (no time and skills to cope)
- S/Ns find it hard to think on individual basis (cling to tasks)
- new C/N needs to police ward to ensure patient safety (check up and supervise)
- staff task oriented (not able to think holistically)
- teaching programme disorganised
- responsibilities not made clear
- lack of appraisal and professional development (not directed)
- old C/N didn't organise key nursing properly (off duty not done with it in mind)
- ward disorganised and lacks leadership to facilitate LPC
- students better able to change practice - less threatened by moving away from tasks
- running two different systems of care (chaos)

Professional conservatism hampers innovation
- hesitation about any suggestion for change
- concern for legal implications (need permission)
- ward not ready for radical changes (H P resources, skills, support groups)
- choose MRCs rather than self medication
- don't want to share contentious information with patients
- consultant reluctant to allow aromatherapy on ward - not wish to endorse
- lack of enthusiasm is a major barrier to moving forward with change
- CNM express caution and conservatism about LPC in practice
- health promotion literature not found to be contentious as originally thought

House officers in at the deep end - unable to cope with change

Lack of managerial support from senior medics
- poor orientation to ward (poor handover)
- lack of monitoring and direction of house officers (just left to get on with job)
- house officers encouraged to be autonomous (not supported, need help)
- senior medics not meeting management responsibilities
- consultant expects C/N to informally, orientate, manage and direct the house officers
- new C/N taking on role of educating and managing house officers
- house officers learn through trial and error - inadequately prepared

- registrar suggests house officers are poorly supervised and lack professional development
- house officers left in at the deep end - poorly supervised (some manage, some flounder)
- medics lack management skills for professional development (task oriented)
- old C/N fed up with reminding house officers what to do

Unable to cope with developing new roles and responsibilities
- house officers not coping with day to day work (not sure what to do or is expected)
- house officers pay lip service to research (would do more if monitored)
- house officers only do what is stressed as being important (glorified clerks)
- house officers not taught to think holistically - cling to tasks to cope

Lack of support for change from nursing management - sweeping issues under the carpet
- hierarchy too busy with other changes e.g. regrading
- other researchers in hospital disillusioned with lack of support from management
- promises not fulfilled (solicitor's letter, LPC statement)
- too busy to deal with known issues - swept under the carpet
- CNM disruptive - does not attend LPC meetings
- CNM and CNM colludes - not addressing issues raised on the ward
- ADNS did not visit the ward as promised to deal with issues raised (S/N complaint)
- career counselling not given as promised (no support for old C/N)
- pay lip service to project - management acknowledge insufficient support
- research supported through opportunistic events (not purposefully managed)
- researcher developing counselling role for old C/N in absence of senior support
- lack of support for staff from hierarchy throughout hospital
- problems identified by research not new (forces ignored issues to be confronted)
- CNM relates to own problems rather than listen to staff issues
- old C/N ignores issues raised by staff
- nursing management reluctant to share findings openly with management colleagues
- tasks being delegated down by management although staff clearly over stretched
- C/N expected to fill in the holes (management not easing the burden)
- new C/N feels isolated, unsupported and exhausted (resents lack of support)
- hard to be innovative when issues raised are ignored
- project not seen as a priority yet new C/N accepted job on this basis
- crisis management - action when forced (no forward and long term planning)
- have to be assertive to get problems addressed (constantly chase things)
- new CNM role means less contact with ward (isolated not appraised and supported)
- lack of feedback (makes one feel vulnerable, let down, angry and demotivated)

Staff lack management skills to support change of practice

- S/N stressed being left in charge (feels unable to do a good job - not in control)
- senior S/Ns not capable of supporting and developing junior staff (lack of role models)
- staff need to develop new management skills to facilitate change (advice and support)
- S/Ns not competent at co-ordinator's role (don't monitor, check up and assess priorities)
- policies on key nursing and LPC not implemented (lack of leadership and commitment)
- S/Ns find it difficult to relate to co-ordinator (not used to feed back nor seeking advice)
- S/Ns lack skills in communication, supervision, teaching and organisation
- staff stuck in a rut (hard to change way ward organised)
- staff unable to offer colleagues support and advice
- S/Ns hiding inability and avoiding responsibility
- S/Ns need supervised experience of being in charge
- S/Ns need to develop educative, supportive and supervisory roles for change in skill mix

Lack of talking and supportive culture to support change

- poor communication within team
- old C/N tends to block and avoid communication (ignores researcher and staff)
- old C/N communicates when confronted (easier to talk through third person)
- members leave ward without informing rest of team (no cohesion)
- meetings like feedback sessions rather than discussions
- impossible to get consultants together to discuss things about ward
- insufficient time to deal effectively with feelings in meetings
- staff not well looked after (basic facilities not provided e.g. tea and coffee)
- misused and unsupported by management
- staff feeling burnt out and unsupported
- inter staff conflict (personality clashes)
- disruptive members in team
- lack of commitment from management to deal with problems and issues
- new C/N exhausted with staff personal problems (personally unsupported)
- researcher developing counselling role for old C/N in absence of senior support
- staff unaware of each others problems (feel demotivated)
- lack of support for colleagues evident throughout hospital organisation
- feel unsupported in trying to change practice (not valued)
- lack of support for C/Ns (not appraised and no opportunity to express feelings)
- lack of support for learners

Staff recognise own need for support to be able to contribute more

- C/Ns demand peer support group (feel vulnerable - roles changing)
- S/Ns drained after supporting patient through emotional experience

- key nursing leads to more meaningful relationships with patients (stressful)
- interviews seen as being therapeutic
- staff go off sick - so stressful
- staff value team meetings as a source of support
- new C/N finds staff development very stressful (wants support from hierarchy)
- old C/N off loads feelings - sense of leaving problems behind

Poor ward learning environment
- students not monitored and supported
- reputation for poor professional practice
- lack of care for colleagues not conducive for learning
- students complain (ward at risk of closure)

Atmosphere on ward not conducive to change
- some staff just coming to work to do a job (lack motivation to change)
- ward staff not doing the basics - difficult to introduce new ideas
- not all nurses dynamic enough to care
- S/Ns feel undervalued (let down by regrading)
- good S/Ns leaving disillusioned

SYSTEM UNABLE TO SUPPORT INNOVATION

Lack of time and resources to support change
- ward busy (no time for research - least priority)
- lack of time for proper discussion and meetings (can't plan better ways to organise)
- staff shortages - no time for research nor for individualised care
- too busy to deal with issues and problems
- paramedics not as involved as would like due to pressures of work
- staff not being replaced - no money and difficult to fill posts (hard to make change)
- staff so busy - no time to think about change and new systems of work
- no money to develop teaching and counselling room
- staffing levels inadequate (wrong skill mix)
- students complain lack of time for teaching, reflection (only give priority care)
- no time to professionally develop and support staff and students
- task oriented nursing reinforced due to inefficiency of hospital (cut backs)
- new C/N frustrated could not have skill mix needed (restricted budget)
- poor standards of care (no linen, porters, pharmacy, staff)
- ward constantly stretched - no good time to make change
- house officers frustrated by obstacles in system stopping things getting done

Change is hard to achieve as a one off in a organisation
- innovation hampered by factors beyond one's control
- can't get essential supplies to support innovation (bureaucracy)
- inefficiency within the system wastes precious time (constantly fight to achieve)
- want to allow lay people make coffee on ward - fear domestics might object
- domestics object to changes in patients' day (affects routine)
- have to really fight to get things done (beds closed and change to professional model)
- new C/N frustrated - not kept informed about issues likely to affect the change
- embedded in unwieldy bureaucracy (individuality lost)
- frustration with effort of trying to fight the system

NHS staff over stretched and stressed - state of crisis and low morale
- trying to keep heads above water just keeping system ticking over (barely coping)
- sense of crisis management in time of stress within NHS (innovation not supported)
- difficult to make changes in current climate (enormous constraints)
- low morale (posts frozen, financial deficit)
- expected to do everything yesterday with hands tied behind back
- tend not to see projects through (sweep under carpet)
- too many meetings in hospital - not getting things done
- individualised care creating too much pressure
- management just coping with own stresses (unable to support others)
- old C/N burnt out (not switching off, no control, exhausted, stressed, demotivated)
- low morale in hospital (fully stretched - can't take on anything new)
- some participants not coping with own roles before change suggested

NHS under constant threat of change - poor environment for innovation
- no room for more innovation within the system
- constant change in NHS (lack consultation, too rapid, no consolidation)
- low morale from too much change being imposed
- no control over changes - being imposed from above (juggling priorities)
- NHS management over loaded with imposed change from above

Organisation not committed to professional nursing developments
- hospital not in line with professional developments (ignores strategy for nursing)
- hospital does not actively support those attempting to develop practice
- innovation seen as deviant - tend to be isolated
- ward had reputation for poor professional practice
- hospital not ready to take on new ideas (coping with cut backs)

Higher demands placed on staff due to NHS changes - no energy for innovation
- new C/N asked to be involved in other changes (needs to concentrate on one thing)
- roles changing (new responsibilities not prepared for)
- old C/N unhappy with way ward C/N role changing
- CNM role changing (away day to examine issues and problems)

LACK OF EVIDENCE OF LPC IN PRACTICE

LPC not actively supported
- old C/N stops patient filling in own charts
- patients' letter not given out and not followed up
- health promotion literature needs to be vetted (medical dominance)
- professional knows best (concern about involving lay support groups)
- family and visitors seen as a problem (getting in the way and too demanding)
- old C/N discourages staff to speak to anxious relative
- old C/N won't bend rules to allow patient to use phone
- lack of acceptance of visitors on ward (not made to feel welcome)
- patients complaining about poor treatment
- conservatism stifling innovation
- patient education low on list of priorities
- house officers ignore family in case conference
- patient ignored on ward round (included only at end)
- lack of professional respect for lay views
- want to talk to alcoholic husband and wife separately
- professional control of information (fear do lay person harm)
- don't address non compliance from patients' perspective (waste of time)
- consultant consults GP re family coping at home (not family)
- patients abilities for self care not assessed (patient angry independence taken away)
- conflict between what patient wanted to achieve and what professionals would allow
- patient not trusted as regards pain threshold
- carer at home not approached about LPC
- lack of contact with and explanations to families (complaints)
- special request of family goes unheeded due to poor communication
- house officers not giving out MRCs (cling to tasks - under too much pressure)

LPC not part of normal practice
- opportunities missed for patient education
- patient education off loaded to specialists

- explanations seen as medics job and for junior staff
- LPC rarely mentioned in report - not discussed (only superficially)
- not all staff aware of patients' family and friends (poor contact with families)
- LPC requires complex skills (listening, assessment, decision making, teaching and communication skills) - staff lack these skills
- professionals not aware of family circumstances - poor contact with families
- students query why patients do not have access to notes
- initiated by patient or family (AIDS leads the way - nurses learn a lot from carers)
- patients and families ill prepared for discharge (inappropriate discharges)
- discharges not properly planned (delays, complaints, readmissions)
- families not involved in care planning
- relatives withdraw from bed on ward round
- tend only to involve family at discharge (sometimes too late)
- health promotion not seen as a priority
- carers at home not involved in care in hospital
- relatives told of poor prognosis (not patient)
- no acknowledgement of patient's worries or how family coping
- MDT vague about what has been told to families
- no mentioning of patients participating in own monitoring
- family not involved when patient undergoing stressful procedure
- no mention of LPC for patient's frequent visitors
- medical communications not conducive to LPC (selective and degrading)

Lack of professional understanding of LPC (unfamiliar concept)

- professional lack of insight into LPC
- no positive suggestions as to how LPC could be encouraged and implemented
- pattern with house officers only realise importance of LPC in 3rd month
- house officers unfamiliar with concept (lack skills to practice LPC,)
- house officers not trained in LPC - appreciate through experience
- professionals do not participate with each other let alone lay people
- not all professionals see patients holistically (tend not to consider social aspects)
- old C/N makes relatives feel guilty if don't take patient home with them
- S/N prescriptive and authoritarian in advice and teaching
- S/N shows lack of understanding of relatives' position in hospital
- interviews gave insight, educational, motivating (confront issues not thought before)
- appreciate the value of LPC when look at personal experience of health care
- professionals don't understand that choosing not to be involved is LPC
- seen as new approach and way of thinking (need help to do this)
- medics find concept difficult to talk about (seen as nursing issue)

- new C/N came to realise LPC was an approach to care (not realised before)
- S/Ns do not understand LPC (lack of training)

Only isolated professionals view LPC as part of normal practice
- D/Ns keen to discuss subject (normally ignored by professionals)
- paramedics see LPC as an opportunity for better teamwork
- paramedics see LPC as part of their normal role
- MDT approach seen as way in which physiotherapists are trained

Doubts about LPC in practice

Lack of positive response to LPC from public
- patients' letter makes no impact (only a minority seem to want LPC)
- professionals suspect lay people may not want LPC
- adverse reaction of family to letter (feel off loading)
- visitors frightened to interfere
- mixed feed back on health promotion literature
- few people with regular visitors able to stay for long periods of time
- patient admitted attempted suicide because family unable to cope at home
- as a patient, medic resented being asked to write own care plan (not his job)
- involvement seen as added burden due to other commitments
- family saw hospital care as a form of respite care
- involvement sometimes leads to conflict between patient and significant other
- family angry that nurses were not more assertive with patient who refused wash
- patient did not want to know about lay support
- family shocked that nurse spoke openly to patient about cancer
- family withdrew (unable to cope with patient dying)

Professional concerns and doubts about LPC
- lay people may feel guilty if don't want to participate
- worry about the legal implications of LPC (boundaries blurred)
- concerned lay people may make mistakes with technical aspects of care
- need to be closely monitored (lay people not do too much)
- staff will need extra support (LPC stressful seeing patients holistically)
- domestics would need education
- society depends on NHS (unsupported by families)
- professionals may not know enough to give information to lay people
- many patients seem to be unsuitable (mental impairment, no visitors, too dependent)
- patient teaching thought to be too time consuming

- professionals might not want to develop educative and supportive roles
- some patients may not be interested in nor understand LPC (medic knows best)
- health promotion material needed to be vetted for mixed messages
- patient outcomes may be affected by involvement (loss of independence)
- social care not seen as important as medical care
- don't expect families will want the extra burden of LPC
- sense of guilt asking relatives to get involved (off loading)
- truth is dangerous for some patients (unable to take poor prognosis)
- LPC not seen as good as professional care (need expertise)
- closer involvement demands more emotional energy - stressful

Lack of skills for LPC

- lack of communication skills to offer LPC as an option (need role model)
- house officers ill at ease talking to patients (though often delegated the task)
- S/Ns find it hard to talk to patients about poor prognoses (lack confidence)
- S/Ns don't know what questions to ask to get a holistic perspective
- student nurses better trained than qualified nurses to discuss LPC with patients
- need good role model for health promotion
- lack of skills for health education and teaching
- nurses not trained for educative and supportive roles (avoid issues not confront)
- tendency to be prescriptive rather than facilitative
- teaching passed on to specialists
- difficult communication situations off loaded onto least experienced
- lack of teaching (inadequate preparation for discharge)
- care plans poorly written
- new C/N concerned S/Ns lack skills to assess patients educational needs
- medical training doesn't prepare for every day practice (learn and leave)
- house officers trained to be task oriented (not holistic in approach)
- S/Ns lack skills and confidence to teach and support learners (never mind patients)
- S/Ns have difficulty organising and managing care
- S/Ns have difficulty assessing, planning and evaluating care
- S/Ns need professional development to fulfil key nurse role
- S/Ns not confident in practice and want development

ISSUES ENCOUNTERED DOING ACTION RESEARCH

Verbal support for research but no commitment

- working alone, feel isolated (lack of co-operation)
- research not high priority (willing but not facilitative)

- not enthusiastic till see changes (not prepared to make the effort)
- lack of understanding about research process
- pessimistic about potential for success
- new systems of work not being supported (key nurse and MRC)
- S/Ns leave without completing questionnaires
- lack of co-operation (meetings cancelled, hard to interview participants)
- staff not reading feedback sheets (no interest)
- remotivated when challenged by apathy - verbal support reaffirmed
- nursing hierarchy acknowledge own lack of support (not visit ward, delay letter)
- new house officers not interested in project (lip service - no reward in being involved)
- old C/N not interested in feedback of findings
- consultant goes on holiday without communicating with researcher
- consultant's lack of interest in research
- old C/N ignoring researcher and research issues (mixed messages)
- not committed unless concept proved - want control trial evidence
- prefer to stick to routines (easier)
- total inertia (verbal support only no action - hard to keep momentum)
- lack of collaboration (researcher doing everything)
- research not seen as real research - want control trial
- researcher's role limited due to lack of commitment
- feedback sheets to be discontinued (too time consuming)
- old C/N seen to be blocking change
- medics would support changes if they saw improvements
- consultant questions if patients on ward are suitable for LPC
- MDT team want to continue project despite issues raised by research (still no action)
- felt need to withdraw (lack of collaboration, presence resented)
- lack power and influence to change things
- researcher's enthusiasm not maintained in her absence
- house officers missing meetings
- pharmacist feeling guilty not more involved with research
- staff vary in enthusiasm for change
- nursing hierarchy verbally supportive of need for teaching and counselling room

<u>Lack of ownership of research ideas inhibiting change</u>

- old C/N wants researcher to write out handout
- offered help Senior Health Promotion Officer - not taken up
- key nurse system failing (staff not pulling together)
- MRC system reviewed - not being done nor evaluated properly (not medics priority)
- new house officers given no explanations about their role

- house officers not going on drug round as asked
- house officers not teaching patients about their treatments
- staff leaving before true ownership of project secured
- takes time to change attitudes and practice

Democratic forms of work create conflict

- S/Ns throw away sorbo rings (old C/N disapproves)
- feel interfering on the ward and in the way (seen as taking over)
- old C/N resents time being taken for research
- old C/N reluctant to change (gives mixed messages)
- old C/N not democratic due to transiency
- old C/N difficult to communicate with (resents researcher)
- too many chiefs not enough Indians (S/Ns adopt authoritarian approach)
- inter staff conflict (S/Ns want to innovate)
- consultant worried decision taken without him (wants to retain power and control)
- old C/N's authority questioned by S/Ns (not collaborating) - feels lack of respect
- old C/N forced to change (career guidance if not)
- research unsettles the ward (talking openly and honestly - painful issues)
- old C/N not prepared to listen and try out to new ideas
- old C/N threatened - disliked democratic approach
- old C/N acting as if no conflict (ignores the issues)
- staff find co-workers too critical
- old C/N feels vulnerable and constantly criticised (defensive about way runs ward)
- openness would lead to conflict on other wards too

Threatening issues raised in process of research

- action research uncovers sensitive issues
- research showed old C/N to not be doing aspects of her job
- old C/N to be given career guidance if not prepared to change (old C/N vulnerable)
- only ward where research being done (old C/N feeling isolated and vulnerable)
- old C/N resented being forced out of job
- research makes participants confront painful issues
- researcher seen as better leader and organiser by staff (threat to old C/N)
- difficult to feedback sensitive issues (uncomfortable)
- change is implied by mere presence of researcher and feedback
- deals with reality (not easy form of research)
- confidentiality can be broken by participants - risk
- old C/N vulnerable (feels furniture has been rearranged in own flat, imposed values)
- S/Ns need positive support and leadership (looked to researcher in absence of old C/N)

- staff turned to researcher with problems (listened) - resented by old C/N
- old C/N felt pressurised by juniors to change (open to public criticism)
- research adding pressure in already demoralised work force
- similar issues may well be found elsewhere (vulnerable through participation)

Participants need confidence to work openly and democratically
- participants need to be able to accept criticism
- participants need to accept democratic approach
- old C/N not open (uncomfortable being interviewed - taped)
- ward uncomfortable talking openly and honestly

Sense of being manipulative
- feel being used by management to solve problems already aware of
- feel responsible for old C/N's situation (scapegoat)
- not possible to gain informed consent (can't anticipate what will happen)
- field notes invaluable source of data (?participants always aware of role)
- need to counsel participants about intended use of the data
- S/N disappointed (project came to nothing) - involved with unrealistic expectations
- many participants have moved on before the end (not see end product)

Relationships between participants and action researcher need constant review
- researcher and participants unsure of role (needs to worked out as part of process)
- uncomfortable role (constant pressure to be accepted)
- role confusion (do things to please - used as pair of hands)
- feel anger towards participants (frustrating - need to be free from bias)
- accepted by some not by others yet need a team approach
- how involved should management be (can be threatening)
- staff fed up change so slow (disillusioned - need to renegotiate commitment)
- requires caring and supportive relationship (personal investment)
- personality clash - researcher seen as too enthusiastic by old C/N
- counselled dying man's wife rather than discuss research
- staff share their problems with researcher (counsellor)
- researcher feels want to give something back (relationship feels unequal)
- S/Ns turn to researcher for advice (lack of leadership) - feel encroaching
- time of uncertainty (not sure of future role on the ward)
- renegotiate acceptance on the ward with new C/N (new stage of project)
- physiotherapy manager concerned about ownership of data

Researcher self doubts - working in isolation

- researcher has self doubts (not feel in control - avoid ward)
- busy but sense of not achieving (disillusioned and fed up - need a break)
- working in isolation (not part of a team - needs support)
- hard to see progress - participants frustrated and disappointed (self doubts)
- learning to have confidence in self and remotivate
- research approach criticised by participants (seen as unscientific)
- feel uncomfortable not sharing everything with participants (job application)
- time of uncertainty (not sure of future role on ward)
- sense of isolation (need to share findings with participants to objectify)
- self doubts part of process of doing PhD
- analysis difficult (personally involved - reliving experience)

Research compromised by not being pre-planned

- hard to think up ideas and be creative on the spot
- not aware of issues at beginning of research (participants not know what agreed to)
- facilitator role too time consuming and requires much effort - affects quality of research
- hard to focus on what to record (constrained by research design)
- exhausted and overwhelmed (hard to keep on top of research process)
- worried about academic integrity of research (crisis of confidence - panic)
- disillusioned and burnt out (feel apathetic)
- research not taken seriously (not controlled trial)
- unsure of quality of research (little time to reflect on data)
- process of research time consuming
- interview not going well - tired (better when tape turned off)
- data collection methods need to be adjusted during project itself
- hard to keep on top of everything (field notes) and think creatively
- need flexibility but wish had something concrete to grapple with
- having to work through issues as they arrive (vulnerable - may get it wrong)
- S/N questions whether achieved more by concentrating on fewer patients
- difficult to identify LPC (need more structured approach - no time to plan for)

Difficult to combine researcher role with practice role

- difficult to gather patient data in limited time before change needs to start
- difficulties combining evaluator and researcher roles
- role confusion - being used to as professional advisor for staff conflict
- difficult being researcher and nurse (feel responsible)
- unable to give sufficient time to either aspect of role
- gathering data time consuming (detracts from practice role)

- writing up field notes is time consuming (takes you away from ward)
- feel know what the issues are but need to prove them systematically
- feel tired and drained (exhausting)
- hard to adjust to doing the analysis

Difficult to withdraw from ward
- hard to break ties with ward when change has just started
- difficult to know when to stop data collection
- sense of need to keep project ticking over (?ownership really established)
- need to pass on project (could easily get sucked into doing more)
- hospital needs to take ownership (researcher needs to withdraw to allow this)

Benefits of action research
- pleased to have flexible methodology to gather process data
- get richer data by being an insider
- dealing with reality (more meaningful)
- participants more willing to co-operate with data collection
- able to establish personal relationship (share more - better access to ward dynamics)

Acceptance of researcher

In general
- welcome and interested in research
- interviews (closer relationship - sense of rapport)
- given confidential information
- clinical credibility (valued member of team)
- understanding of role
- involved in ward gossip
- feel part of team (feel able to offer ward something)
- feedback of findings make them less personal and researcher less threatening
- acceptance of findings by participants
- problems not because of research (old C/N wanted to leave before, previous complaints)
- staff share problems and feelings with researcher (counselling role)
- value of being an insider (collect informal data in field notes)
- accepted as an insider (share problems - recognise skills as a nurse)
- easier to get questionnaires back as an insider
- action research depends on trust (able to speak freely - more able to reassure)
- not always easy to be tape recorded - helped that knew views informally

By nursing hierarchy

- good relationship with ADNS
- acceptance by DNS (asked to go on advisory committee)
- nursing hierarchy suggest researcher apply for senior research post
- hierarchy want research to continue (created new post to support innovation)
- DNS offers part time work to researcher to continue research
- CNM happy for researcher to have access to records (treated as insider)
- CNM speaks openly and honestly at interview
- feel less alienated from CNM (helpful towards project)
- interview seen as being therapeutic
- CNM found interview helpful to get things into perspective

By C/Ns

- old C/N pleased with researcher (pleased with paperwork being done)
- positive relationship with old C/N (no apparent resentment after confrontation)
- old C/N willing to share thoughts honestly (atmosphere less tense - off load feelings)
- old C/N more positive and co-operative with research
- honest and open relationship with new C/N (collaborative - wants change)
- new C/N wants to work with researcher (chose ward because of this)
- old C/N had no apparent resentments (made to feel welcome at leaving party)
- trust is vital (helps to be known form the past)
- new C/N wants it to be known that project was her reason for taking job
- new C/N articulate and open (easier to relate data)

By staff nurses

- S/Ns offer support to researcher (appreciate difficulties in role)
- S/Ns appreciate researcher's enthusiasm and don't want project to fail
- S/Ns understand need to support old C/N through change process
- better accepted when old C/N not there
- S/Ns need enthusiastic person to motivate and direct them
- S/Ns went to ADNS because want change on the ward
- S/Ns feel learnt a lot from researcher as a role model
- S/N feeling guilty because leaving (cares about research project)

By multidisciplinary team

- renegotiated position on ward (MDT want researcher to stay)
- team suggest researcher applies for old C/N's job
- problems of doing non medical research starting to be appreciated
- consultant more accepting of sociological research

By medics

- medic suggested needed persuasive leader like researcher
- consultant concerned researcher frustrated due to lack of change

POSITIVE CHANGES ACHIEVED

Participants willing to co-operate with research ideas in theory

- S/Ns trying to change practice (willing to co-operate)
- old C/N understands problems when explained
- old C/N states she wants to change documentation
- consultants and medics support research ideas in public
- S/Ns want to introduce Primary Nursing (way of putting policy into action)
- interviews gain support for ideas (think things through)
- old C/N sees research as lightening own burden
- old C/N unusually contributed at meeting - not threatened
- DNS wants community informed (community enthusiastic -to help informal carers)
- meeting with DNS, ADNS and C/N to discuss legal implications
- new C/N more co-operative when hierarchy involved and away from the ward
- MDT discuss new systems of organising work (key nurse)
- medical commitment to drug education (design MRC system)
- health promotion unit offer help and support
- paramedics support research ideas in theory
- S/Ns initiate meeting to get project moving (enthusiastic for change)
- people accepting responsibility for change (empowering)
- S/Ns feel time well spent on research
- old C/N wants research to continue (reservations but not against ideas being tried)
- old C/N showing signs of being positive in meetings (approves orientation handout)
- formal support for research ideas (statutory bodies)
- formal support from management for research to continue (part of wider change)
- nursing hierarchy want to be at feedback session to medics and attend meetings
- nursing hierarchy suggest application for regional monies to continue evaluation
- true collaboration with new C/N (research and innovation)
- new C/N takes ownership of project ideas (wants to develop research, register for PhD)
- S/Ns feel guilty letting research down by leaving
- nursing hierarchy show ownership of project ideas (ADNS - innovation in hospital)
- ADNS visited ward to reassure staff project would continue
- old C/N supports research continuing despite resigning
- house officers become more positive in third month of being on ward

- sense of researcher withdrawal and passing on ownership to participants
- new C/N sees research as way of changing practice (enthusiastic)
- new C/N welcomes not working in hierarchical manner
- MDT meetings seen as therapeutic
- new C/N recognises need for teaching to be included in care planning
- MDT pleased new C/N applying for regional and DoH money to continue evaluation
- consultant delighted with new C/N's appointment (would lead research forward)
- sense of passing on ownership and monitoring of project to new C/N (able to withdraw)

Qualitative difference in ward C/Ns - key to change

- *old C/N seen as problematic*
  - poor relationship with school and students
  - reluctant to change in past (likes status quo)
  - ignores research findings and new developments
  - feels threatened by new things (not confident)
  - poor relationships with staff (complaints)
  - lack of personal and professional development
  - feels to be in a rut (demoralised and unhappy)
  - lack of communication skills
  - lack of teaching skills
  - lack of self confidence to get out of rut
  - felt insecure with new ideas in nursing
  - ward C/N role changing (found job difficult)
  - poor motivator (initiatives floundered)
  - not committed to research ideas (blocks others)
  - lacked enthusiasm and skills for change (no ideas)
  - poor leader of change (poor team leader)
  - not capable of organising key nurse system
  - just going to work to do a job

- *covering C/N has professional approach*
  - knows patients well,
  - assertive for high standards,
  - encourages nurses to contribute ideas
  - positive atmosphere

- *new C/N more dynamic*
  - interested in staff professional development
  - good relationship with medics (more assertive)
  - assesses, plans and evaluates care in theory and practice
  - encourages development of educative and supportive roles

- encourages and supports nurses to make decisions
- excellent communicator and leader (personality and skills)
- ward better organised (learnt to delegate and be decisive)
- reflects on practice and suggest new ideas
- committed to own professional development (degree)
- not threatened by change (collaborates and participates)
- wants to change and improve care (feels committed)
- welcomes new experiences (keen to learn - innovative)
- assertiveness training led to new perspective and degree
- intellectually able to be creative
- self confident (honest, open and self critical)
- committed to nursing as a profession (enthusiastic)
- adaptable (recognises need to change ward C/N role)
- strength and skill to redirect and develop staff
- supportive, sensitive, caring to patients and colleagues
- copes with busy ward (diffuses tension)
- assertive and dynamic
- allows S/Ns to realise their own potential
- identifies and develops strengths and weaknesses in staff
- plans off duty to accommodate new ideas
- relates well to medics (gets their commitment)
- acts as a role model (counselling skills)
- sensitive (aware of need to change things slowly)
- recognises importance of good communication
- sees action research as a form of quality assurance
- willing to give own personal time to support project
- works in facilitative manner (encourages initiative)

Change in ward C/N viewed positively

- S/Ns pleased and shocked at old C/N's resignation
- old C/N enthusiastic about new job (ready for change)
- lack of rapport between old C/N and medics
- ward ready for change in leader (need to develop S/Ns to facilitate LPC)
- old C/N leaving: - unhappy in role, felt criticised even before project
- S/Ns appreciate changes (want to learn from new C/N)
- CNM views change positively (old C/N not coping with job)
- consultants delighted with choice of new C/N (known and respected)
- old C/N ready to change (didn't like way ward C/N role had changed)

Multidisciplinary team working together

- meetings established for feedback (nurses and MDT)
- feedback of initial findings to MDT led to policy
- DNS holds meeting with old C/N for feedback and plan policy statement
- sense of general co-operation from most staff
- night staff stock up leaflet rack
- LPC meetings established to discuss individual patients and potential involvement
- S/Ns encouraging MDT involvement in care and feedback
- S/Ns being more assertive in MDT
- medics less territorial (willing for aroma therapist)
- registrar supports nurses' new system of work
- registrar welcomes MDT meetings (form of psychotherapy)
- communications on ward improved - less hierarchical
- consultants making small changes to accommodate ward
- developing team spirit - better working relationships
- medics communicating with specific staff about individual patients
- new C/N discusses more with consultants what she wants to achieve on ward
- MDT meeting will be continued as good to discuss ward issues (positive outcome)
- S/Ns using orientation handout with new staff
- S/N suggests nurse attends AIDS meeting for better co-ordination
- MDT member feels more welcome on the ward
- more equality in relationships (can discuss nurse and medic power)

Ownership of change - C/N and consultant facilitating change

- old C/N facilitating change in meeting through allowing discussion
- old C/N agrees to new documentation (S/Ns want to learn - enthusiastic)
- consultant reinforced some issues raised in feedback
- consultant accepts health promotion literature as non contentious
- consultant suggests patients put in touch with support groups
- new C/N taking ownership of project (time for researcher to withdraw)

Ward learning environment improved for students

- initiative shown (mentor system introduced for students - educate about LPC)
- teaching programme started
- S/N organises support session for learners
- mentor system at last introduced (liked by students)
- positive feedback from learners (like key nurse system and mentor system)

Staff initiating own ideas

- S/Ns recognise too dependent on me as leader (want to take more ownership)
- S/Ns responsible for meetings to introduce key nurse system
- S/Ns want to initiate change (place of report, mentor system, teaching)
- MDT involvement in planning patient letter informing about LPC
- medics suggest patients go home with discharge summaries
- handover document being written by house officers - orientate to ward and research
- hospital trying to own research ideas (support new appointment for research)
- nursing hierarchy create senior post to disseminate project ideas
- S/N initiative - contacts AA about teaching sessions on counselling alcoholics
- S/N initiative - finds out about primary nursing MRC system
- S/N writes off duty with key nurse system in mind
- S/N wants to be present when her patient is told about poor prognosis to support
- S/Ns more enthusiastic (want to make changes before new C/N arrives)
- social worker gets money from League of Friends for relaxation tapes and cassette player
- social worker organising aroma therapist for relaxation
- S/N contacts Polish volunteer to take patient off ward for a break
- S/Ns suggest patients be informed of their entitlements (recognised unlikely to ask)
- S/Ns have good ideas (need leadership and development)

Changing Attitudes

- changing attitudes (realise change in approach to work needed)
- staff more motivated - contributing positively and enthusiastically
- medics recognise need for change (old systems of care not working)
- recognition that change takes time
- staff realise need new way of thinking for LPC
- S/N only realised had changed when left the ward and compared self with others
- consultant changing views on drug self administration and nurses' contribution
- S/N changed thinking about nursing (better relationships with patients)
- staff more positive to concept of team nursing
- S/Ns appreciate changes (want to stay to learn from new C/N)
- S/Ns pleased with individual feedback on their work (want to change)

Patient education being viewed more positively

- MRC s being given out if not evaluated - seen as being of value
- patient readmitted (knowledgeable about drugs - important because no record)
- S/Ns want to develop their role in patient teaching
- consultant recognises need for MRC (checks up on house officers)

- patient returned to accident and emergency with MRC (useful)
- patient education is mentioned more in report
- consultant feels failing if not to give education (aware of patients' poor knowledge)

Ward work better organised
- key nurse system starting to work
- off duty written around teams (easier to facilitate LPC)
- implementing less task and routine oriented care (more patient centred)
- patients' day restructured
- staff given more management experience
- standard of written document improving
- S/Ns better able to organise own work and prioritise care
- patient care thought to be improving
- new C/N introduces team nursing and develops skills to facilitate LPC

Creating a talking culture
- S/Ns meet to discuss documentation, teaching and relationships
- S/Ns discuss ways can support old C/N through change process
- S/Ns initiate support and informative meetings for students
- consultant reads feedback sheets on return from holiday
- S/Ns encouraged to talk more about their feelings
- improved communication on the ward (less hierarchical)
- staff better able to constructively criticise each other
- new C/N encourages students to meet to discuss problems
- S/Ns becoming dependent on new C/N for support

Better awareness of patients and families
- consideration shown for family taking dying patient home
- patient helped to come to terms with condition by key nurse
- recognition that patients need to be better prepared for discharge (more insight)
- recognition that family needs are not considered enough - too patient centred
- report more interactive (know patients better, teach students more, emphasise social)
- S/N suggests remove suction debris (not nice for family)
- recognition that patients need to be asked (won't always express needs in hospital)
- S/N suggests family talked to about poor prognosis and offered support
- S/Ns recognise need to sit down with families and sort out discharge plans
- consultants feel research has changed their awareness of patient care
- families identified as needing support
- S/N feel guilty when family's request goes unheeded

Lay participation in care in practice

- examples of LPC discussed in report
- patient education takes higher profile (recognised as part of care planning)
- S/N organises case conference to include patient and family
- S/Ns more involved in patient and family information giving
- patients' individual views being respected (involved in decision making)
- patients involved in monitoring own fluid balance
- patients and family given contact numbers of local support groups
- paramedics involving families in their work
- families involved in giving physical nursing care
- patient given leaflet to explain procedure
- patients family mentioned in terms of visiting
- partner allowed to share bed of dying AIDS patient
- patient thought to be improving as a result of patient education (breathing exercises)
- relatives more involved in care (act as though belong on ward more)
- physiotherapist involves relatives in rehabilitation
- signs of innovation finally being implemented
- MRC system thought to be useful with complex drug regimes
- key nurses give good feedback on individual patients at report
- details of LPC appearing in kardex
- LPC seen as better than professional care
- learn a lot from AIDS (leading the way)
- social circumstances being discussed on ward round
- MDT asking about family and friend involvement for patients
- house officer talk to patient about LPC (keen to be involved)
- family present in diet education
- LPC not new - in practice elsewhere (need to systematically develop)
- patients being seen as individuals more (care more patient centred)
- detailed bed side handover - involve patients in planning care

Staff feel more confident with skills for lay participation in care

- S/N feels more aware of facilities in the community
- S/N feels more confident and better able to communicate with lay people
- S/N feels forming better relationship with patients
- S/N able to discuss death with AIDS patient and facilitate contact with family
- S/N started teaching programme with patient and continued it into community
- S/Ns developing confidence - accept more responsibility

Ward's reputation improving

- old C/N more open to criticism (attended first student evaluation at school)
- mentor system at last introduced (liked by students)
- communication thought to be improved
- old C/N more positive in meeting (foster team spirit)
- consultant less dominant and more participating in meeting
- MRC system getting positive feedback informally (GP wants to use them)
- health promotion resources being used by patients from other wards
- S/Ns feel more positive to work (don't want to go back to old ways of doing things)
- change of C/N viewed positively (old happier in new job and new improving ward)
- positive feedback from learners (like key nurse system and mentor system)
- family see ward as having changed (more involved and more flexible)
- Once left find can plan discharge better, work collaboratively, speak own minds
- new C/N in control more (reputation improved - well run ward)
- positive feedback on way ward developing
- students feel patients are better prepared for discharge than on other wards
- relatives write to ward to thank for special care
- family see ward as having changed (feel more involved, visiting more flexible)

Improved ward experience for students

- change of atmosphere on ward (students happier - new C/N more supportive)
- students feel more involved with and committed to patients
- mentor system introduced
- written ward objectives for students

APPENDIX XXIII

FINDINGS FROM THE WARD LEARNING ENVIRONMENT RATING SCALE

Introduction

The Ward Learning Environment Rating Scale, (Fretwell, 1982) was used to assess the ward learning environment (see Appendix XIV). The questionnaire was designed to rank wards into "good" and "less good" wards from a teaching and learning point of view. It followed a design used by (Bendall, 1973) and sought opinions on the following areas:

- what there was to learn
- what nurses felt they had learnt
- whether they felt all learners would benefit from working on the ward
- teaching by the ward sister, consultant and clinical teacher
- supervision of new procedures
- how the ward compared to other wards
-whether they liked working on the ward.

This tool consists of 9 sets of statements concerned with nurse training in the ward situation. The learner is expected to ring one statement closest to his or her own view for each of the sets of statements. The statements are worded in such a way that it is possible to identify a "good" ward learning environment and in this research study it was used to ascertain if there were any perceived differences in the quality of the ward learning environment of the ward under study over time. The questionnaire was modified slightly to include a few extra questions at the end to ascertain a more open ended response. Learners were asked to comment on how they felt about working on the ward, how they felt about the patient care on the ward and whether they saw patient care on the ward to be any different to other wards.

The ward under study was not thought to have a good ward learning environment at the beginning of the project since concern had been expressed by the school of nursing about its suitability for learners and some participants had indicated the same at interview. This was therefore thought to be one area which was likely to change during the period of the study which could be measured. Given that this research study was about introducing lay participation in care and that this entailed health professionals changing their roles from "doer" to "educator and supporter", measuring the ward learning environment seemed an appropriate indicator of change. In order to offer lay participation in care, the health

professionals would need to ensure that the staff coming into contact with the patients were well informed. Attention would need to be paid to be the learners' understanding of patient needs and ward practice. To facilitate this learning and the education of patients an improvement in the ward learning environment would be essential. The questionnaire format was chosen for expediency since it was not thought possible to release learners from ward work for interview. I decided to monitor the ward learning environment throughout the project so that changes could be monitored over time. All learners who were staying on the ward for more than 4 weeks and who were not first warders were asked to complete the "Ward Learning Environment Rating Scale" (Fretwell, 1982). These learners were selected since they needed to have worked on the ward for a period of time (4 weeks) before they would be able to make comment on ward practice and also to have worked on other wards to be able to make the ward comparisons asked for in the questionnaire. This questionnaire was designed for use with learners only and so was not given out to any other participants. The transient nature of their work means that they frequently change wards (usually every 8-10 weeks) and are therefore best place to assess the differences between wards as a learning environment. A total of 21 questionnaires were given out and 18 were returned representing a response rate of 86%.

The data were analysed using the statistical software package SPSS-X and non parametric hypothesis tests were used. Basic descriptive statistics were used to summarise the data and frequency distributions were then performed to look at the spread of the data. Scatter plots were used to look at each question over time. Each question was then correlated with the each of the other questions using the Spearman rank correlation coefficient. The Spearman rank correlation coefficient was used in preference to the Pearson correlation coefficient on account of the non normal distribution. The Spearman rank correlation coefficient requires a random sample of subjects (unless the sample is not biased) , paired samples and independent observations within each sample. Following this each question was correlated against time using once more by means of the Spearman rank correlation coefficient.

Table 88 summarises the frequency of responses to each item and thus provides descriptive contextual data as regards the learners perceptions of the ward as a learning environment. This table does not take account of time and so the findings are an amalgamation of responses throughout the year of data collection.

Table 88: Ward Learning Environment Rating Scale

Frequency of responses to each item

		Value	Freq	%	Valid %*	Cum %**
1a	There was very much to learn on this ward	4	3	16.7	17.6	100.0
1b	There was a lot to learn on this ward	3	11	61.1	64.7	82.4
1c	There was quite a lot to learn on this ward	2	3	16.7	17.6	17.6
1d	There was hardly anything to learn on this ward	1				
	blank	9	1	5.6	MISSING	
	Valid cases: 17, Missing cases: 1	Total	18	100.0	100.0	
2a	The doctors were definitely not interested in teaching nurses	1	1	5.6	5.9	5.9
2b	The doctors were really not interested in teaching nurses	2	4	22.2	23.5	29.4
2c	Some doctors were quite interested in teaching nurses	3	9	50.0	52.9	82.4
2d	Some doctors were very interested in teaching nurses	4	3	16.7	17.6	100.0
	blank	9	1	5.6	MISSING	
	Valid cases: 17, Missing cases: 1	Total	18	100.0	100.0	
3a	Not many learners would benefit from working on this ward	1	2	11.1	11.8	11.8
3b	I don't really know if other learners would benefit from working on this ward	2	1	5.6	5.9	17.6
3c	I think most learners would benefit from working on this ward	3	12	66.7	70.6	88.2
3d	I think all learners would benefit from working on this ward	4	2	11.1	11.8	100.0
	blank	9	1	5.6	MISSING	
	Valid cases: 17, Missing cases: 1	Total	18	100.0	100.0	

* Valid % takes into account the missing values

** Cum % = Cummunlative Percentage

Table 88: continued

		Value	Freq	%	Valid %*	Cum %**
4a	The qualified nurses taught me many things	4	1	5 6	5.9	100.0
4b	The qualified nurses taught me lots of things	3	4	22.2	23.5	94.1
4c	The qualified nurses taught me quite a lot of things	2	8	44.4	47.1	70.6
4d	The qualified nurses hardly taught me anything	1	4	22.2	23.5	23.5
	blank	9	1	5.6	MISSING	
	Valid cases: 17, Missing cases: 1	Total	18	100.0	100.0	
5a	There was always someone to supervise new procedures	4	2	11.1	12.5	100.0
5b	There was usually someone to supervise new procedures	3	9	50.0	56.3	87.5
5c	There was sometimes someone to supervise new procedures	2	5	27.8	31.3	31.3
5d	There was rarely anyone to supervise new procedures	1				
	blank	9	2	11.1	MISSING	
	Valid cases: 16, Missing cases: 2	Total	18	100.0	100.0	
6a	I learnt little on this ward	1	1	5.6	5.9	5.9
6b	I learnt quite a lot on this ward	2	9	50.0	52.9	58.8
6c	I learnt a lot on this ward	3	6	33.3	35.3	94.1
6d	I learnt very much on this ward	4	1	5.6	5.9	100.0
	blank	9	1	5.6	MISSING	
	Valid cases: 17, Missing cases: 1	Total	18	100.0	100.0	
7a	Clinical teachers taught frequently on this ward	4	1	5.6	5.9	100.0
7b	Clinical teachers taught sometimes on this ward	3				
7c	Clinical teachers hardly ever taught on this ward	2	2	11.1	11.8	94.1
7d	Clinical teachers never taught on this ward	1	14	77.8	82.4	82.4
	blank	9	1	5.6	MISSING	
	Valid cases: 17, Missing cases: 1	Total	18	100.0	100.0	

* Valid % takes into account the missing values

** Cum % = Cummunlative Percentage

Table 88: continued

		Value	Freq	%	Valid %*	Cum %**
8a	This is the best ward I have worked on	4	1	5.6	5.9	100.0
8b	This is one of the best wards I have worked on	3	4	22.2	23.5	94.1
8c	This ward is no worse and no better than other wards I have worked on	2	7	38.9	41.2	70.6
8d	This is one of the worst wards I have worked on	1	5	27.8	29.4	29.4
	blank	9	1	5.6	MISSING	
	Valid cases: 17, Missing cases: 1	Total	18	100.0	100.0	
9a	I did not like working on this ward	1	2	11.1	11.8	11.8
9b	I did not mind working on this ward	2	4	22.2	23.5	35.3
9c	I liked working on this ward	3	7	38.9	41.2	76.5
9d	I liked working on this ward very much	4	4	22.2	23.5	100.0
	blank	9	1	5.6	MISSING	
	Valid cases: 17, Missing cases: 1	Total	18	100.0	100.0	

* Valid % takes into account the missing values

** Cum % = Cummunlative Percentage

Table 89 summarises the frequency of responses to each item in relation to time. Spearman rank correlation coefficient was used to analyse this data. The Spearman rank correlation coefficient measures the degree of linear association between the ranks of two variables. The closer the population Spearman rank correlation coefficient is to -1 or 1, the stronger the linear component of the relationship between ranks of the variables. If the population Spearman rank correlation coefficient is 0, the ranks of the variables can still be strongly related in a non-linear way.

Table 89: Ward Learning Environment Rating Scale

Spearman Correlation Coefficients (questions in relation to time)

	Time		Time		Time
Quest 1	.5004 N(17) SIG.020 *	Quest 2	.6408 N(17) SIG.003 *	Quest 3	.2371 N(17) SIG.180
Quest 4	.4302 N(17) SIG.042 *	Quest 5	.5750 N(16) SIG.010 *	Quest 6	.2621 N(17) SIG.155
Quest 7	-.2191 N(17) SIG.199	Quest 8	.3692 N(17) SIG.072	Quest 9	.6468 N(17) SIG.003 *

***: significant at the 5% level**

From Table 89 it can be seen that Questions 1, 2, 4, 5 and 9 were all significantly correlated (at 5% level) in relation to time. All significant findings were positively correlated. Examination of scatter plots indicated linear relationships between variables suggesting that over time the ward learning environment improved on the ward. It should be noted that in general, correlations are low (except for Questions 2 and 9) and there is some scatter. However there would appear to be a link between time and an improvement in the ward learning environment, although clearly other variables were having an effect.

APPENDIX XXIV

FINDINGS FROM THE NURSING PROCESS MEASURING SCALE: WARD NURSES' SELF-RATING SCALE BROOKING (1986)

Introduction

The Ward Nurses' Self Rating Scale is part of a larger Nursing Process Measuring Scale (Brooking, 1986). This scale is sufficient to give an indication of the use of the nursing process in a ward setting. This scale was used not only to provide contextual case study data in order that the reader might be in a better position to judge the relevance of the findings to his or her own practice setting but also as a measure of change. Given that patient and their close family and friend involvement in care is central to the nursing process, it was envisaged that as lay participation in care was introduced on the ward the scores for the nursing process would increase.

The Ward Nurses' Self-rating Scale (Appendix XV) consists of 37 items requiring respondents to state to what extent certain nursing process activities are carried out on the ward using a Likert scale with the categories of "yes, always/excellent", "yes, usually/good", "yes, often/fair", "sometimes, poor", "don't know" and "no, never".

The scale was completed by 32 nurses (14 qualified nurses and 18 nurse learners). As the nursing process is an approach to nursing it was thought to be inappropriate to give this questionnaire to other multidisciplinary team members. The questionnaire was given to nurses at the beginning of the study and to nurses as they joined the ward team throughout the year. It was therefore possible to look at changes on the ward in relation to the nursing process over time. The findings were analysed using non-parametric statistical procedures in the SPSS-X software package.

Table 90 summarises the frequency of responses to each item and thus provides descriptive contextual data as regards the extent to which the ward was being viewed by participants to be doing the nursing process. This table does not take account of time and so the findings are an amalgamation of responses throughout the year of data collection.

Table 90: Nursing Process Measurement Scale

Frequency of responses to each item

		blank %	yes, always/ excellent %	yes, usually/ good %	yes, often/ fair %	some times/ poor %	don't know %	no, never %
1.	Is an assessment made of new patients, prior to planning and giving care?		9.4	40.6	31.3	18.8		
2.	Is a written nursing history taken, using a specific form?		25.0	31.3	31.3	9.4		3.1
3.	Does the nursing assessment begin within 24 hours of admission?		28.1	28.1	34.4	9.4		
4.	Are nursing problems identified and written down for all new patients?		25.0	15.6	18.8	37.5		3.1
5.	Are potential and/or possible problems identified as well as actual problems?	3.1	6.3	34.4	18.8	37.5		
6.	Is an attempt made to find and record the causes of patients' problems?			34.4	12.5	46.9		6.3
7.	Are problem statements arranged in order of priority?			15.6	34.4	43.8	3.1	3.1
8.	Are problem statements made with the knowledge and agreement of patients and/or relatives?	3.1			6.3	40.6	15.6	34.4
9.	Are written care plans produced which incorporate patients' problems and/or needs?		3.1	37.5	34.4	21.9		3.1
10.	Are care plans up dated daily?		3.1	15.6	21.9	31.3		28.1
11.	Are nursing care planning discussions or rounds held on the ward?			3.1	3.1	31.3	3.1	59.4
12.	Do care plans include discharge planning?		3.1	12.5	6.3	31.3		46.9
13.	Are goals (nursing objectives) incorporated into the care plans?		9.4	21.9	31.3	31.3	3.1	3.1

Table 90: continued

14.	Do the goals include both long and short term goals?			6.3	25.0	46.9	3.1	18.8
15.	Are goals agreed upon with patients and/or relatives?				9.4	28.1	9.4	53.1
16.	Are goals written in terms of patient outcomes i.e. change in the patient?	3.1	3.1	12.5	25.0	37.5	3.1	15.6
17.	Do goals specify a time element for achievement?	3.1			15.6	40.6		40.6
18.	Are problem-oriented planned nursing actions included in care plans?		9.4	28.1	34.4	21.9	6.3	
19.	Are planned nursing actions agreed upon with patients and/or relatives?	3.1		12.5	21.9	31.3	6.3	25.0
20.	Are planned nursing actions written in detail?	3.1	12.5	21.9	9.4	37.5		15.6
21.	Are patient allocation or primary nursing used throughout the ward at all times?	6.3	3.1	12.5	28.1	25.0	3.1	21.9
22.	Are nurses allocated to the same patients for several days?		21.9	53.1	25.0			
23.	Are care plans used for the verbal ward handover reports?		9.4	28.1	15.6	12.5		34.4
24.	Are written nursing progress reports based on patients' problems and goals?	3.1	6.3	28.1	21.9	28.1		12.5
25.	Are nurses responsible for written and verbal reports on their patients?	3.1	31.3	43.8	15.6	6.3		
26.	Do nurses take part in medical rounds for their patients?	3.1		3.1	12.5	53.1	28.1	
27.	Are care plans used both day and night as a basis for giving care?	6.3	6.3	15.6	21.9	28.1	9.4	12.5
28.	Is systematic evaluation of care carried out for all patients?	6.3		25.0	25.0	25.0	3.1	15.6
29.	Is evaluation recorded on the care plans or progress notes?	12.5	12.5	18.8	21.9	21.9		12.5

Table 90; continued

30.	Are dates for the evaluation of patients' problems included in the care plans?	3.1	3.1	6 3	9.4	46.9		31.3
31.	Are objective measures of patient progress used on the ward?	25.0			15.6	34.4	9.4	15.6
32.	Are patients and/or relatives included in evaluation?	6.3			12.5	25.0	12.5	43.8
33.	Are care plans modified according to the results of evaluation?	3.1		15.6	21.9	50.0	6.3	3.1
34.	Have study days or lectures been held to teach nursing progress to permanent ward nurses?	3.1	3.1	3.1	6.3	6.3	53.1	25.0
35.	Have all permanent ward nurses attended at least one study day or lecture on nursing progress?	6.3		3.1	6.3	3.1	75.0	6.3
36.	Is nursing process taught to learners in the school of nursing?	6.3	21.9	37.5	15.6	6.3	9.4	3.1
37.	Does the sister/charge nurse involve nurses in decision-making and delegate responsibility?	3.1	3.1	34.4	40.6	18.8		

Table 91 summarises the frequency of responses to each item in relation to time. Spearman rank correlation coefficient was used to analyse this data. The Spearman rank correlation coefficient measures the degree of linear association between the ranks of two variables. The closer the population Spearman rank correlation coefficient is to -1 or 1, the stronger the linear component of the relationship between ranks of the variables. If the population Spearman rank correlation coefficient is 0, the ranks of the variables can still be strongly related in a non-linear way.

Table 91: Nursing Process Measurement Scale

Spearman Correlation Coefficients (questions in relation to time)

	Time		Time		Time
Quest 1	-.3953 N(31) SIG.014 *	**Quest 2**	-.2864 N(31) SIG .059	**Quest 3**	-.3673 N(31) .021 *
Quest 4	-.5948 N(31) SIG.000 *	**Quest 5**	-.6270 N(30) SIG.000 *	**Quest 6**	-.3537 N(31) SIG.025 *
Quest 7	-.2503 N(31) SIG.087	**Quest 8**	-.3711 N(30) SIG.022 *	**Quest 9**	-.5987 N(31) SIG.000 *
Quest 10	-.5713 N(31) SIG.000 *	**Quest 11**	-.4565 N(31) SIG.005 *	**Quest 12**	-.1714 N(31) SIG.178
Quest 13	-.4272 N(31) SIG.008 *	**Quest 14**	-.2283 N(31) SIG.108	**Quest 15**	-.2421 N(31) SIG.095
Quest 16	-.2364 N(30) SIG.104	**Quest 17**	-.1932 N(30) SIG.153	**Quest 18**	-.2953 N(31) SIG.053
Quest 19	-.3801 N(30) SIG.019 *	**Quest 20**	-.4751 N(30) SIG.004 *	**Quest 21**	-.3372 N(30) SIG.034 *
Quest 22	-.0983 N(31) SIG.299	**Quest 23**	-.5969 N(31) SIG.000 *	**Quest 24**	-.6236 N(30) SIG.000 *
Quest 25	-.4465 N(30) SIG.007 *	**Quest 26**	.3380 N(30) SIG.034 *	**Quest 27**	-.5115 N(29) SIG.002 *
Quest 28	-.6496 N(29) SIG.000 *	**Quest 29**	-.5671 N(27) SIG.001 *	**Quest 30**	-.4281 N(30) SIG.009 *
Quest 31	-.2620 N(23) SIG.114	**Quest 32**	-.4901 N(29) SIG.003 *	**Quest 33**	-.4025 N(30) SIG.014 *

Table 91: continued

Quest 34	-.3220 N(30) SIG.041 *	**Quest 35**	.0277 N(29) SIG.443	**Quest 36**	-.1101 N(29) SIG.285
Quest 37	-.1912 N(30) SIG.156				

*: significant at the 5% level

From Table 91 it can be seen that Questions 1, 3, 4, 5, 6, 8, 9, 10, 11, 13, 19, 20, 21, 23, 24, 25, 26, 27, 28, 29, 30, 32, 33 and 34 were all significantly correlated (at 5% level) in relation to time. With the exception of Question 26, all significant findings were negatively correlated. Examination of scatter plots indicated linear relationships between variables suggesting that over time the nursing process scores improved on the ward. On the other hand Question 26 was positively correlated and this suggests that over time nurses were taking less part in medical rounds for patients. It should be noted that with the exception of Questions 4, 5, 9, 10, 11, 13, 20, 22, 24, 25, 27, 28, 29, 30, 32; correlations are low and there is some general scatter. However nonetheless there would appear to be a significant link between time and an improvement in nursing process scores, although clearly other variables were having an effect.

Lay participation in care: a challenge for multidisciplinary teamwork

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Summary *This paper draws on case study data from research exploring the introduction of lay participation in care within the context of a ward environment. In this action research study I worked with a multidisciplinary team on a general medical ward in a London teaching hospital, for a period of one year, in an attempt to foster a change in practice that would involve patients and their family/friends in care in hospital, with a view to better preparation for discharge. Lay participation in care is seen as a major thread of health promotion and whilst the research highlights many of the issues and problems concerned with trying to develop health professionals' educative/supportive roles, this paper concentrates on the findings that suggest a lack of multidisciplinary teamwork was an inhibiting factor in trying to change ward practice. Whilst case study findings cannot be generalised, the issues that will be raised in this paper include a lack of professional commitment to lay participation in care and factors that inhibited change on the ward, namely, the effect of transiency, the existence of functional rather than developmental models of health care practice, a lack of multidisciplinary team leadership and poor multidisciplinary team collaboration due to medical dominance.*

Key words: *Action research; lay participation in care; medical dominance; multidisciplinary teamwork; task oriented practice; transiency.*

Introduction

Lay participation in care is fundamentally concerned with the involvement of non-professionals in hospitals, institutions and/or the wider community. McEwen describes participation in care as:

> —the process whereby a person can function on his or her own behalf in the maintenance and promotion of health, the prevention of disease, the detection, treatment and care of illness and adaptation to continuing disability. It may occur independently of, or within, the existing system of care and extends to activities performed on behalf of others (eg family participation) and in the planning, management and evaluation of health care provision (McEwen, Martini & Wilkins, 1983)

Lay participation in care is thus seen as a major thread of health promotion (Kickbusch, 1981) and is concerned with patient empowerment. It acknowledges a change in relationship between the professional and lay person, emphasising partnership. Within the literature the term is used to describe various phenomena related to health care practice, drawing from a

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range of disciplines (medical sociology, health psychology, social policy, health promotion, nursing, medicine) The body of knowledge on this subject is therefore somewhat fragmentary and inconclusive Research on lay participation in care covers a wide variety of activities/approaches/facets as reviewed by Brearley (1990) Often it focuses on one aspect of care in relation to participation, for instance patient education (Wilson-Barnett & Osborne, 1983), self monitoring (Nelson, 1977), self medication (Webb, Addison, Holman, Saklaki & Wagner, 1990), compliance (Craig, 1985), goal setting (Janz, Becker & Hartman, 1984) A few studies have examined the concept as a total approach to care such as those evaluating the cooperative care units in North America (Grieco, Garnett, Glassman, Valoon & McClure, 1990) Sometimes it can focus on the individual (activated patient, Schulman (1979)), whereas at other times it can focus on the patients' family/friends (informal carers, Parker (1985)) or on the wider community itself (community participation, Madan (1987))

The concept of lay participation in care is currently popular However, on closer scrutiny there is only weak evidence of meaningful partnerships between health professionals and the lay public Within nursing, partnership is currently a key issue as specified in the Strategy for Nursing document (Department of Health, 1989a) and underpins the new courses in nurse education (United Kingdom Central Council for Nursing, Midwifery & Health Visiting, 1986) Within the health service the concept is further promulgated in the form of "patient as consumer" (Department of Health, 1989b) However there is a concern that in some cases participation is viewed as mere tokenism (Brownlea, 1987) or as manipulation towards compliance with medical treatments (Brearley, 1990) Furthermore it has been suggested by some nurse researchers that not all patients may wish to participate in care and may find themselves coerced as reluctant collaborators (Waterworth & Luker, 1990) A review of the literature reveals much rhetoric and few empirical studies (Brooking, 1986)

Despite the lack of sufficient research evidence to support current policy directives to involve consumers in care (Department of Health, 1989b), it is recognised that due to demographic changes and social expectations new approaches to health care need to be devised To truly involve patients and their family and friends as partners in care, it is essential that there is a commitment from all professional groups using an interprofessional perspective This paper draws on data that illustrates the factors that promote and inhibit lay participation in care

Methodological approach

Using illuminative evaluation strategies (Parlett & Hamilton, 1977) and an action research approach (Elliott, 1991), I worked together with a multidisciplinary team on a general medical ward in a London teaching hospital for a period of one year I negotiated access to the study ward on the basis that the participants were interested in implementing lay participation in care and were willing to have me work as part of their multidisciplinary team in the role of facilitator/evaluator of change Action research is a form of new paradigm research (Reason & Rowan, 1981) and is concerned with doing research *with* and *for* people rather than *on* people It supports the notion that the advancement of science and the improvement of human welfare is best achieved by devising strategies in which research and action are linked Studies therefore involve practitioners in the identification of their practical concerns and in exploring ways of overcoming issues It seeks to involve practitioners in the creative thinking that goes into a research enterprise by giving opportunity for participants to act as co-researchers, by contributing both to the action which is the subject of the enquiry and to the methods of the inquiry Action research depends upon the participants taking an active part in the planning and evaluation of the innovation, therefore weekly team meetings were set up with participants to discuss the project ideas As it was not possible for all the

nurses to attend this meeting, other meetings took place during the week for them to discuss issues raised by the multidisciplinary team

Context of the study

The ward was located in a London teaching hospital and was managed by a nurse who had been in post for eight years and was supported by ten qualified nurses, one part time auxiliary, one part time ward clerk and eight nurses for allocation periods of 8–10 weeks (50% of whom were on their first ward experience) There were two consultants who had each been in post for over 10 years and who had a team of one senior registrar, one registrar and two house officers Named paramedical staff (dietitian, occupational therapist, pharmacist, physiotherapist, speech therapist and social worker) were allocated to the ward but in addition had responsibilities for other wards in the hospital Patients tended to come from the local community and represented a rich mix of age, social class and ethnic backgrounds

During the period of the study the hospital was under pressure to improve efficiency and service to patients while keeping within a reducing budget It was in the middle of the turmoil following the first Griffiths report when major changes were occurring in the National Health Service and senior nurses were feeling threatened (Robinson, Strong & Elkan, 1989) It was at the time of the regrading exercise and nurses at all levels were being asked to look at their job descriptions, roles and responsibilities In addition Project 2000 proposals were being debated and participants were feeling apprehensive as to how they were going to address this major educational reform Within the hospital the workload had generally increased with the fixed establishment not accommodating the increase in demand for care A nearby hospital had been closed and posts were being ring fenced for the future amalgamation of staff from the two separate sites The ward clerks were in the middle of a two year dispute and working to rule The cleaning had gone out to tender and staff were having to contend with support services offering a less than adequate service Pressure was on to reduce waiting lists and there was a movement towards thinking about trust status An overall top down approach to change as well as the need to adjust to new ideas and roles was contributing to low morale

Given that so much change was being forced from above, it could be argued that a bottom up approach to change, such as that used in an action research approach, might have empowered participants to cope better with their situation The focus of my approach was non-directive and facilitative In this way I set out to enable participants to examine their practice and reflect on new ways of giving care

Data collection

In line with an illuminative evaluation which sets out to examine phenomena from a variety of different angles, a multi-method approach to data collection was taken including questionnaires, interviews and participant observation recorded in daily field notes

During the year as staff members changed data were gathered from 18 qualified nurses, 17 learner nurses (excluding learners on their first ward allocation), 14 medical staff, 13 paramedical staff and 8 senior nurse managers (community) who were kept informed of the study but were not actually considered as participants in the change process

The qualified multidisciplinary team members were interviewed at the beginning and end of the study or as members joined or left the team throughout the year The aims of the initial interviews were to, firstly, ascertain the health professionals' perceptions of lay participation in care and, secondly, to establish what changes participants wished to make on the ward in order to facilitate this approach to care Interview data on the professionals'

perceptions were supplemented with data generated from a scale designed to measure attitudes towards the concept ("Patient and Family Participation in Nursing Care Scale" (Brooking, 1986)) together with data generated from participant observation field notes The interviews at the end of the study aimed at evaluating the health professionals' perceptions of the innovation in terms of factors that had helped or had hindered developments From the initial interviews a ward policy on lay participation in care was drawn up for discussion and refinement by the team In addition a number of previously validated measures were employed before and after the innovation to describe the extent of change over the year These included an analysis of the ward learning environment (Fretwell, 1982), use of the nursing process (Brooking, 1986) and quality of nursing care (Phaneuf, 1976, Wandelt & Ager, 1976) However, this paper will not report these findings as very little change occurred in the course of the year that could be detected by the measures used

The focus of this paper will therefore concentrate on the process factors rather than the outcome measures In particular it will address the lack of professional commitment to the concept of lay participation in care and the limitations of interprofessional work to foster change in practice

Lack of professional commitment to lay participation in care

In this study, health professionals initially showed a keen interest and had volunteered to take part in an action research study aimed at promoting lay participation in care. However it later became apparent that it constituted a radical change to practice and for many maintaining the status quo was the preferred option The majority of the multidisciplinary team appeared to have a limited understanding of the concept, they found it difficult to articulate what it meant and to think of how it might be implemented As one nurse said

> I think it's a really good idea . and at the same time I think it's difficult, or I find it difficult to know what sort of tasks to give them to do and sometimes I find myself hanging on to all because that's my role and you know it's easy to hide behind the sort of nurse's role, I can do all this and get on and do it, and it is more difficult and perhaps takes longer to involve them in care SN4(I)p 2

Whilst the results from Brooking's attitude scale indicated that health professionals held positive views towards lay participation in care, triangulation of this data with that from the interviews and field notes revealed that, when probed deeper, health professionals held some serious reservations about applying the concept in their own health care practice This research therefore questions the use of such scales to measure complex phenomena It would appear that what health professionals say in theory about lay participation in care could be indeed very different to what they really feel when confronted with the notion in practice

Apart from the paramedical staff who saw lay participation in care as part of their job and claimed experience of the concept in their rehabilitation work, other health professionals generally reported that they had not encountered it before It is interesting to note that the nurses tended to agree more in their views about lay participation in care compared to the other health professionals

At interview health professionals found it hard to articulate and conceptualise what was meant by lay participation in care Generally they found it difficult to relate to its philosophical underpinnings and its link with health promotion instead they focused more on better understanding and compliance with medical regimes Most patients were thought to be suited to this approach to care and particular mention was given to those suffering from strokes, alcoholism and AIDS/HIV Lay participation in care was thought to lead to improved recovery rates and better continuity of care It was also seen as a means of making the

experience of being in hospital more positive and of reducing the work for health professionals and thus being more cost effective although they found it hard to suggest ways in which lay participation in care might be facilitated on the ward

However, serious reservations about the concept included a fear that patients and families may not wish to be involved and might perceive health professionals as abrogating their responsibilities This was linked to a concern over the possible invasion of patients' privacy and for the legal implications Lay participation in care was seen as an idealistic concept Furthermore health professionals feared that it would be time consuming and upset their routines and as such was perceived as a threat to the status quo As one house officer said

> I think all of us are probably a little reluctant to allow relatives, non-members of our professions, to be involved in patient care we might tend to think right, things are probably going to get messed up, our routine is going to be messed up, we'll have to share all our idiosyncrasies and our frustrations and all the rest with the relatives and they'll see what we are really like, whereas we want to retain our respectability and so there may be quite a few hidden reasons why the flesh is weak MD7(I)p 9/10

Observation of practice revealed little evidence of lay participation in care Patients did not have access to their notes or care plans and complained of a lack of day-to-day information about their care Talking to lay people about their care was not seen as high status work and was generally delegated to junior members of the team who lacked the skills and confidence to deal with it competently The multidisciplinary team was frequently unaware of the patients' social situation and on occasion this resulted in inappropriate discharge Furthermore lay participation in care was seen as a potential threat to professional practice For instance medical staff were reluctant to allow the development of non medical ideas on the ward Aromatherapy was viewed with scepticism as being unscientific and health promotion leaflets had to be vetted to prevent conflicting messages Professionals showed a lack of commitment to lay participation in care since it required too much effort on their part to implement, being time consuming and potentially more stressful It was thus a threat to the status quo and health professionals found that they did not have the skills or confidence in their professional practice to develop more educative/supportive roles with patients and their family/friends One of the reasons why it was not possible to develop these skills was due to the limitations of interprofessional work to foster change in practice

Limitations of interprofessional work to foster change in practice

Throughout the study the findings from interviews and field notes revealed a team reluctant to change, lacking cohesion and exhibiting all the signs of "dynamic conservatism" (Schon, 1971) At the beginning participants identified the need for sharing of knowledge and expertise with lay people in order that they might be able to take more of an active role in care However, there was a concern amongst the professionals that knowledge and expertise were inadequately shared amongst themselves As one nurse said

> I think on the whole both doctors and nurses are terrible at giving out information to relatives and patients, and I think I would like to see the nursing staff being able to give out a lot more information and being able to talk through it with the relatives rather than the doctors coming round on ward rounds and in five minutes telling so and so what's wrong with them or what they're going to do But I also think we're kept in the dark until the last minute and then we're expected, you know, to answer the relatives' questions and we don't know what's going on SN5(I)p 5/6

Mills (1990) suggests that the essence of collaborative practice is "the mutual exchange, integration and use of ideas which lead to optimal patient care, process and outcome" This research revealed that despite a multidisciplinary team attempting to foster collaborative practice through the mechanisms of action research, various factors inhibited this process which are described as follows

Transiency

The single most important factor inhibiting change on the ward was undoubtedly the transient nature of the work-force Being a teaching hospital, staff were often rotating around the wards to gain experience and staying for only short periods of time During the course of the year there were only five members of staff remaining in post at the end of the study who were there at the beginning This transiency made innovation and continuity of care difficult As one paramedic said

> I was probably there too short a time to really grasp hold of the whole thing, because I was probably more interested in getting to know the patients myself and worrying about the physio side rather than any other side, so to be quite honest I probably didn't take much notice of what the other multidisciplinary how they what they were actually doing as part of your research thing, so I probably didn't notice what was going on MD20(E)p 8

Many staff were allocated to work on the ward for only three months at a time, which they found too short As one doctor said

> I think it was very difficult to get a grasp of the working of the ward. It takes time Three months, I think, has been just sufficient for me to feel comfortable now and if I was to stay another three months, it would be a lot easier MD31(E)p 3

As new staff struggled to come to terms with their positions on the ward, they were not inclined to consider ways in which they might be better able to work together and change practice Instead they made themselves busy behind a screen of task oriented practice Menzies (1988) discusses how health professionals develop social defence mechanisms and hide behind task oriented practices to avoid experiences of anxiety, guilt, doubt and uncertainty and Procter (1989) links this to an ever changing workforce

Functional rather than developmental models of practice

It has been suggested that a functional and task oriented model of practice has important advantages for managing care when the care is given by a semi-skilled, transient workforce (Davies, 1977) However, this traditional approach to the organisation of nursing work is thought not to be reconcilable with patient centred approaches to care (Procter, 1989) Lay participation in care is clearly patient centred and as such requires a more developmental model of practice in line with "the new nursing" ideology (Beardshaw & Robinson, 1990) Lay participation in care constitutes a change in role for the health professional from one reliant on getting work/tasks done to one more concerned with flexibility and developing educative supportive skills to foster individual patient care

Early on in the study some participants identified the need to change the way in which the ward was organised in order that lay participation in care could be better facilitated It was suggested that a modified system of primary nursing would be most appropriate Primary nursing involves patients being allocated to a named qualified nurse who is responsible and accountable for co-ordinating specific patients' care and who has the autonomy to make

decisions with the patient about care (Ersser & Tutton, 1991). This required a shift in thinking and working of the entire multidisciplinary team, which some found difficult. As one house officer said:

> I think you have to observe . . . routines and . . . my job . . . at times there seems almost too much to do and I just get on with sticking needles in people and making sure they've signed their consents when they go to theatre, but I don't kind of see it as kind of holistic . . . maybe I should do but I just don't think I have the time or the resources available to think more about the patient and his environment. MD17(I)p.21

Nurses were similarly set in old routine and task oriented habits and found it difficult to change. Several suggested that they had just been going to work to do a job and had lacked enthusiasm for change. As one nurse said:

> I think a lot of things on this ward have just been done over the years and perhaps not much thought has gone into it and I think we all need to be a bit more enthusiastic about what we're doing and where we're going rather than just carrying on in the old way. SN5(I)p.9

Lay participation in care was thus a threat to the status quo and health professionals found that they did not have the skills, confidence or energy in their professional practice to develop more educative/supportive roles with patients and their family/friends. To overcome this the need for an enthusiastic leader to manage interprofessional change was identified. However, closer examination of the multidisciplinary team revealed that there was no one person in a position of power and responsibility who was fulfilling this role.

Lack of multidisciplinary team leadership

Whilst the consultants were seen as being in charge of patient care, they did not appear to perceive themselves as leaders of multidisciplinary change on the ward. They felt they had too little contact with the ward and saw this as being the role of the nurse in charge. However, in spite of issues being discussed on a weekly basis at project meetings, no one took overall responsibility for leading the change. For instance there was no agreement between the consultants and the nurse in charge over who should 'chivvy' the junior doctors in their general ward work. Thus the junior doctors were not closely monitored and often they neglected their roles in the change process as they did not see it as a priority. An example of this is the initiative taken by the medical staff to improve patient drug education on the ward using a medicine reminder card as an *aide-mémoire* and drug record. It was intended that this would allow patients to be more involved and promote understanding of treatments and ultimately, compliance post discharge. However without the close supervision from their senior colleagues this initiative was ignored. Junior doctors failed to realise the importance of patient education until the end of their three month allocation and by then it was time for them to move on. At the end of this allocation on the ward, one doctor reflected:

> I think one of the main values (of the project) and it may seem an odd thing to say is that it has brought home to me how little often the nurses and the relatives understand what we are doing. In other words, part of it has been educational for me in demonstrating what a huge gulf there is, often between us and the nurses, in terms of understanding what we are trying to achieve, as well as between us, the nurses and the relatives . . . and the patient, who clearly half the time hasn't a clue

> what we are doing. So I think that is the first thing; educational for me. MD23(E)p.3

Several junior doctors commented that they had felt unprepared for their roles on the ward, having been given little in the way of handover or support from their senior colleagues. For many orientation to the ward constituted a short period with the previous junior doctor discussing the patients but not ward practice. This lack of managerial guidance and development was supported by comments from a senior colleague who said:

> But I think the problem is that you have someone, often you have never met before, coming in as a houseman. They frequently start without any handover at all. They are given a great sheaf of information that they have to take over. A lot of them may have had no experience before but some of them are very inexperienced and often very frightened by their inexperience and it takes them a long time to settle down. They are told so many things it is very difficult when you are told all these things to know which are the most important. The rest of us are so busy we don't always realise the problems they are having and the things they are doing and the things they are not doing. Three months is such an appalling short time to have them. It's not surprising that things don't even start to get right until just before they leave. MD2(E)p.3/4

Similarly within the nursing team there was lack of managerial support and guidance for junior nurses to develop their educative/supportive roles with patients. This led to frustration and apathy within the team towards the project and ideas for change.

The final issues affecting the ability of the multidisciplinary team to work together were to do with power and social control.

Medical dominance inhibiting multidisciplinary team collaboration

Medical dominance became a key issue in this study. Whilst doctors looked to the nurses to lead changes in ward practice their status and influence in the multidisciplinary team meant that nurses deferred to medical authority and were inhibited about making changes. This deference to doctors by nurses has been identified before (Katzman & Roberts, 1988, Mackay, 1990). At project meetings, medical staff (in particular senior members) dominated discussions and nurses, paramedical staff and junior doctors were reluctant to engage in debate. When they didn't agree with decisions they tended to discuss the issues outside the meeting and informally with me. For instance one paramedic said with reference to the consultant:

> I think people are just slightly intimidated, they don't want to say what they feel in front of somebody who might be in a position to criticise them, or to say well why do you say that. I don't think that. You don't want to get into a confrontation situation with your superiors I suppose. MD13(E)p.8/9

Again junior medical staff showed a similar caution in expressing opinions to authority figures for fear of being penalised in their future careers. As one house officer said:

> Oh I don't want to upset people like consultants, I mean I wouldn't dream of saying 'I don't think you should take students on your ward rounds because it upsets the patients' . . . they'd say 'Don't tell me I'm a consultant' . . . I wouldn't get a good reference . . . selfish . . .' MD17(I)p.21

This reluctance to engage in debate and state opinions reinforced a hierarchy of power

relations within the team. It appeared to stem from a process of socialization and be accepted as normal practice. As one doctor suggested of nurses:

> I think most nurses, like medical students, have a lot of their ability for individual thought drummed out of them in the last two years of training. You see them as students all bouncing around and bubbly and enjoying themselves and by the time they've got their stripes they've become much more stereotyped and very few of them will stand up and say, 'Well, that's nonsense', or have the confidence on a ward round to say, 'Yes, I think this, yes I think that' so somehow I suppose it comes . . . I haven't actually said the word morale yet, it comes under that heading and it's all this business of people feeling that they have a worthwhile part to play, they've got worthwhile information to give and they should be encouraged to give it. MD4(I)p.16/17

It is difficult to see how any change could be developed, let alone the encouragement of lay participation in care, without professionals learning to participate and collaborate more together.

Conclusion

By the end of the study year some positive changes could be detected. In particular health professionals perceived their attitudes had changed and that they were starting to approach their work in a more patient-centred manner. Communication within the team was also thought to have been improved, with nurses being asked more directly for their opinion on their individual patients' care. However, as with other case studies of change in the National Health Service (Stocking, 1985) the process was extremely slow and it could not be claimed by the end of the study that lay participation in care was being professionally led any more than it was at the beginning. In view of this pessimistic picture and the need to challenge the status quo in order to meet current health care demands (Dingwall, Rafferty & Webster, 1988), it is important that policy makers establish ways in which professionals can learn to work more closely together with a common strength of purpose and thorough understanding and appreciation of each other's roles and responsibilities.

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New paradigm research in practice: the trials and tribulations of action research

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MEYER J.E. (1993) *Journal of Advanced Nursing* **18**, 1066–1072
New paradigm research in practice: the trials and tribulations of action research
This methodological paper reflects on the way in which nursing research has developed along similar lines to research in education. It focuses on the emergence of action research as an example of collaborative research within the practice discipline of nursing. Action research is placed in the framework of new paradigm research and questions concerning its scientific merit are addressed along with its idealistic value to nursing. Drawing on issues raised during the collection of data for a PhD study which examined a changing ward culture, I hope to share some methodological concerns about the use of action research as a means of changing practice.

INTRODUCTION

In this action research study I worked together with a multi-disciplinary team on a general medical ward in a London teaching hospital for a period of 1 year, in an attempt to foster a change in practice, which would increase involvement in care by patients and their family and friends with a view to better preparation for discharge. This case study used a multi-method approach to data collection and explored the challenges encountered by participants as they attempted to move away from a professionally dominated, task-oriented culture to a more patient-centred culture, in which lay participation in care could be facilitated.

However, this paper concentrates mainly on issues raised in the process of doing the research and raises questions about action research that do not appear to have previously been addressed in the nursing literature (statement based on perception by author).

ORIGINS AND DEVELOPMENT OF ACTION RESEARCH

It is often claimed that the term action research was first used by a social psychologist named Kurt Lewin in 1946. However, Corey (1953) suggests that Collier, Commissioner for Indian Affairs 1933–1945 was another independent proponent of action research. Lewin felt that the research needed for social practice should be a form of social management or social engineering.

In his seminal paper, Lewin (1946) placed much emphasis on the need for practical joint studies between social scientists and practitioners, aimed towards social change through a problem solving approach. Lewin identified a framework for action research which included a four stage spiral of steps — i.e. planning, acting, observing and reflecting — and this framework can be seen as a basis for many of the more modern definitions of action research (Carr & Kemmis 1986, Clark 1972, Ebbutt 1985, Elliott 1991).

Action research was and continues to be used in many different disciplines (Kingsley 1985, Rapoport 1970), but the development of action research in education is of particular interest to nurses owing to the parallels that can be drawn with nursing research. It would appear that formal evaluation research in education did not exist before the Second World War and it was a concern over the lack of scientists that led to a closer scrutiny of educational practices (Lacey & Lawton 1981). According to Lacey & Lawton, researchers in education naturally turned to the

discipline of behavioural psychology and borrowed its positivist notions of science to develop their research methodologies in much the same way that early nurse researchers copied the experimental approaches of medicine.

However, theorists in both disciplines were quick to realize the limitations of the empiricist tradition in dealing with human beings within complex organizations and, to some extent, rejected utilization of quantitative approaches with their unrealistic reliance on objectivity and control of variables in favour of the more qualitative approaches of the social sciences. These qualitative methodologies which derive from the 'interpretive' tradition of social enquiry were based on social phenomenology and replaced the scientific notions of explanation, prediction and control, with the interpretive notions of understanding, meaning and action (Carr & Kemmis 1986).

During the 1960/1970s in education (Parlett & Hamilton 1972) and the 1980/1990s in nursing (Field & Morse 1985), qualitative research proliferated and drew heavily on the 'grounded theory' approach of Glaser & Strauss (1967). However frustration with these methods arose both within education and nursing which led to a renewed interest in action research.

At this time, action research had moved on from the earlier ideas of Lewin (1946) and more modern definitions place it very much in the new paradigm tradition of collaborative research which itself emerged through a rejection of the empiricist and interpretivist notions of science (Reason & Rowan 1981).

According to Reason (1988) new paradigm research is concerned with doing research *with* and *for* people rather than *on* people. It is not treated as a neutral, value-free process but as a supporting and questioning initiative. It represents a systematic quest for understanding which as an action science involves learning through risk taking.

McNiff (1988) traces the development of action research in education and shows how it has moved on from Lewin's functionalist approach, through an interpretive tradition led by Stenhouse (1975) and into new paradigm perspective where the current emphasis is placed on the practitioner as researcher. Whereas the more traditional approaches often relied on external researchers acting as consultants in prescribing practice, more modern approaches encourage practitioners to act as researchers by systematic reflection on their everyday practice. These ideas are incorporated in the definition of action research by Carr & Kemmis (1986):

> Action research is a form of self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own practices, their understanding of those practices, and the situations in which those practices are carried out.

Similarly the changes in conceptual understanding can be traced in nursing action research studies. Towell & Harries (1978) who pursued action research on change in a psychiatric hospital drew heavily on the work of Kurt Lewin through his association with the Tavistock Institute, and Lathlean & Farnish (1984) might be described as having taken an interpretive approach in their evaluation of a ward sister development project, whereas current action researchers involved in evaluating the introduction of primary nursing (Bateup 1990, Binnie & Titchen 1990) claim to collaborate more with participants in self-reflective enquiry. As within education there is a current emphasis on reflection-in-action in nursing in order to produce different professional knowledge, more appropriate to practice (Schön 1983). Action research is seen as a means of systematically developing this knowledge in order that it can be shared with practitioners.

Scientific merits of action research

Throughout the last 50 years action research has enjoyed various levels of acceptability and on occasions has been criticized as not being scientific and thus not worthy of the label of 'research'. The next part of the paper will address this issue before going on to look at the value of this type of research to a practice discipline. Having argued the need for action research in nursing, I shall then highlight some of the practical issues and problems experienced when carrying out this type of research based on my own experience. These emphasize the need to exercise caution when using new paradigm research.

Action research as part of new paradigm research has links with feminist scholarship (Callaway 1981). It tends to rely more heavily on the skills of the enquirer, with the approach being more personal and interpersonal than methodological. New paradigm research shows awareness and respect for the integrity of individuals and represents a philosophical approach to research based on a humanistic view of nature. It has also been linked with Habermas's critical social science (Carr & Kemmis 1986) and as such rejects positivistic notions of rationality, objectivity and truth. Critical social science emphasizes the need for self-reflection amongst practitioners and thus its theory development depends on the meanings and interpretations of participants. Its practices are based on democratic participation and its fundamental concern is with identifying and exposing those aspects of the social order over which

participants have no control. It seeks to enable practitioners to overcome their problems and eliminate their frustrations and as such is viewed as being political Carr & Kemmis 1986).

In a male-dominated society with a historical tradition of positivist science, it is not surprising that this type of research is frequently brought into question as being unscientific and more concerned with professional and personal development than research-based practice. Susman & Evered (1978) address this issue in a classic paper entitled 'An assessment of the scientific merits of action research'. They begin by highlighting the deficiencies of positivist science and go on to show that actions and their consequences cannot be explained by the positivist criteria of scientific explanation. The authors suggest that action research can be legitimized as science by locating its foundations in philosophical theories which differ from those used to legitimize positivist science.

Susman & Evered (1978) draw on philosophical approaches such as praxis (art of acting upon the conditions one faces in order to change them), hermeneutics (art of interpreting languages, culture and history), existentialism (asserts the importance of human choice and values), pragmaticism (doctrine that estimates any assertion solely by its practical bearing upon human interests), process philosophies (asserts no two actions are the same on account of constant change) and phenomenology (insists on the primacy of the immediate subjective experience as the basis for knowledge) to explain their case.

Finally, Susman & Evered (1978) go on to explain the contribution of action research to growth of knowledge through the development of 'practics'. The latter concentrate on 'knowing how' rather than 'knowing that' and the authors argue that this type of knowledge is rarely gained through traditional scientific methods. Rather than generalizing prescriptively about the wider population, this type of research generates principles and guides for dealing with different situations. The reader of in-depth case studies is left to decide their relevance to themselves in their own situation. Susman & Evered believe that practics has far greater potential than positivist science for generating knowledge and understanding and for managing affairs in a practice discipline.

McNiff (1988) addresses the claim that action research is no more than personal professional development by suggesting that it is the manner in which the practice is carried out that makes it research. She argues that by making practitioners more aware and critical of their practice and open to a process of change and improvement, they then start to develop theories and rationales for their practice which allow them to give reasoned 'u tification for their public claims to professional knowledge. The writer goes on to suggest that it is this systematic enquiry made public which distinguishes the activity as research.

Schön (1983 identified a crisis in professional knowledge, suggesting that in some professions, awareness of uncertainty complexity instability, uniqueness and value conflict has led to the emergence of professional pluralism. The emergence of these different perspectives has forced professionals to be less confident in relying on the dominant epistemology of practice namely technical rationality, and Schön argues the need to move towards a different epistemology, namely reflection-in-action.

It would appear that the findings from more traditional modes of research are being questioned as relevant for practice. In nursing, Greenwood (1984) questioned the relevance of past nursing research findings to practice and urged researchers to consider using more action research. In this way, research findings would be more accessible to practitioners and more relevant to the realities of their everyday work. Given that research is not widely read by nurses (Hunt 1981, Roper 1977, Smith 1979), Greenwood argued that only then would improvement in practice be possible through research.

From a humanistic perspective, the movement towards more collaborative research is desirable and may indeed lead to a different and more worthwhile type of knowledge. However, this type of research is by no means easy and it should be noted that nursing action research studies in the past have not tended to address the practical issues and dilemmas that make this type of work problematic.

A notable exception is Webb (1989), whose work clearly and sensitively reflects upon her personal experi ences of carrying out action research, offering an honest portrayal of some of the methodological dilemmas. I hope to share some of my experiences in this paper and thus add to this body of practical knowledge.

ISSUES AND PROBLEMS IN ACTION RESEARCH

The action research study I was engaged in was concerned with lay participation in care which, for the purposes of this study, meant the involvement of patients and their family/ friends in hospital care. Given the difficulties of actually identifying a setting in which lay participation in care might be occurring I decided to attempt creation of an environment conducive to lay participation in care through an action research approach examining the issues and problems surrounding this from the different participants per spective. I wanted to engage in a multi-d sciplinary study,

believing that health care could not be divided neatly into nursing, medical and paramedical aspects.

For the initiative to be meaningful, I therefore needed to find a ward where all the members of the multi-disciplinary team were interested in lay participation in caring for their patients and were willing for me to work with them on a daily basis for a period of 1 year as a researcher/facilitator of change. I decided to go back to a hospital where I was known in order that the participants could have some knowledge of me whilst selecting whether to work with me in the study. I also wanted to be accepted as an 'insider' rather than as an 'outsider', given the collaborative nature of the action research process.

The process of negotiating access to a ward was long and arduous. It took 62 interviews over a period of 6 months to establish the self-selection of a suitable ward and even then I am not convinced about the ethics of this selection owing to concerns about the limits of informed consent.

Limits of informed consent in action research

The issue here for me concerns the extent to which participants can truly give informed consent, when the nature of the proposed change is unknown and determined by an emerging reality. Consent really centres around the participants' willingness to take part in the project ideas and acceptance of the researcher as a facilitator of change. The proposals for change come from within the group of participants and as such is a step into the unknown for individual players.

Informed consent is therefore not really possible and once the project is under way it is difficult for individuals to withdraw as they are part of a group committed to working together for change. In other types of research individuals are able to refuse participation without feeling under undue pressure to conform. A questionnaire can be ignored or an interview cancelled. In a participant observation study not dependent on changing practice, the players can act in whatever way they choose without feeling that their behaviour is necessarily affecting others.

In action research, the change is usually dependent on the team pulling together and as such places individuals in a vulnerable position of forced co-operation with their colleagues. This is clearly at odds with the sentiment of action research which relies on willing and voluntary collaboration. One might glibly say that the way around this problem is for the researcher facilitator to withdraw during the study if his her presence becomes unwelcome or the project ideas are not working. However, this is a Utopian concept as the discomfort of one or a few individuals may not leave the rest of the team wishing to call a halt to the project.

Where then does the researcher's loyalty lie? Should it be with vulnerable non-co-operative individual(s) or with the remainder of the team who have invested considerable personal time and energy into the project and do not wish to see their efforts come to naught? Change is potentially threatening and perhaps it is insufficient to get people's agreements to participate in an action research study without first exploring in more detail ways forward in the cases of conflict or reluctance to change. Time should also be spent considering the possibility of unknown issues which may emerge from within the team and how this might affect each player.

Action research can be threatening because of the suggested changes that emerge and also because of the nature of the collaborative relationship between researcher and participant, as will be discussed below.

Potentially threatening nature of a collaborative relationship between researcher and participants

Collaboration implies equality of relationship between researcher and participant which theoretically is not present in other forms of research. Empirical research is concerned with prediction and control and requires the researcher to keep a distance from subjects so as not to contaminate findings. These are owned and interpreted by the researcher and only shared as a finished product. Within the interpretive tradition of social science, concern is more with meaning and understanding; the researcher takes account of the actor's perspective but still maintains control, judging what is said against the researcher's own framework of reference. Collaborative approaches assume that research is done *with* and *for* people rather than *on* people, but I would question to what extent this is possible in reality.

In my study I had negotiated access to the ward on the basis that members of the multi-disciplinary team were willing to work with me as a researcher facilitator in creating change that would facilitate lay participation in care. I specified that I did not want to impose my ideas but to help them to identify the changes they wished to make and then facilitate the process of change. I negotiated that if they became uncomfortable with my presence at any stage I would offer to withdraw. I promised to share the data throughout the study and said that I would not publish any findings that they did not wish to share with others. In this way I hoped to redress the unequal balance of power in the researcher–participant relationship. I would argue, however,

that it is not possible to redress this power relationship in reality.

As a participant observer working on the ward, I found myself ever ready to listen to people's stories in case they had something relevant to say on the subject of lay participation in care. I spent much of my time selling myself as a facilitator, giving people time and support in whatever way was needed. By acting as an insider, I showed that I had understanding and expertise in their area of work and was anxious to gain credibility as a practitioner as well as a researcher.

In essence I became everybody's best friend. However, as Webb (1989) found in her study, there were problems with communication on the ward and the inevitable personality clashes and this placed me in the invidious position of recipient of much personal knowledge. However neutral one tries to be in this situation, one cannot avoid the fact that this type of information gives you power and as such is threatening to others.

The researcher also has the power of not being a full member of staff and knows that whatever change occurs it will not permanently affect them. The researcher is safe in the knowledge that, whatever happens, data will be gathered and the research report will be written (subject, of course, to the participants' approval but it is unlikely that they will withdraw this from a friend!).

The researcher is also powerful by being seen as an academic expert belonging to another world with which not all participants will be familiar. This lack of knowledge on the participants' part means that they may not have a true understanding of the data being gathered (despite one's willingness to share it!) and again this places the participant in a vulnerable position in relation to the researcher. This vulnerability is compounded by the fact that the researcher is likely to have gained wider approval for the study to take place within the organization and this factor is potentially threatening for any participant wishing to withdraw.

It is issues like these that make one suspect that despite the intention to offer an egalitarian relationship with participants, these new paradigm methods place the subjects at far more risk of exploitation, betrayal and abandonment than more positivist research. Stacey (1988) makes the same point when she questions whether there can ever be a feminist ethnography. She writes:

> I find myself wondering whether the appearance of greater respect for and equality with research subjects in the ethnographic approach masks a deeper, more dangerous form of exploitation .. precisely because ethnographic research depends on human relationship engagement, and attachment it places research subjects at grave risk of manipulation and betrayal by the ethnographer

Talking culture

In my own research the democratic processes gave rise to a talking culture that had previously not existed before and the nurse in charge found this to be a particular challenge. As one participant said of the nurse in charge:

> ... and this negativism all the time. She's frightened that someone is going to usurp her she wants the power and she's frightened of new ideas ... I m sure that's why she is so negative about it. Because otherwise I d have thought she'd receive it with open arms, anything that's constructive is worth it. No one's criticizing her, it's not a personal assault at all, but her attitude is just affecting everyone. It could be just such a good ward because you get good material to teach on and interesting patients and nice staff.

From her perspective, she had not been able to anticipate the kind of changes that the rest of the multi-disciplinary team would want to make in order to introduce lay participation in care. The fact that the researcher was present asking for suggestions and feeding back the issues in an open and honest way thus had a profound effect on the group dynamics. It made everyone re-examine their roles and responsibilities.

For some members of the team this was an extremely painful experience after many years of less-questioned practice. It made me question whether I had the right to be the catalyst of such unwelcome unrest. Even offering to withdraw did not solve the problem: most participants wanted the project to continue and the nursing management insisted that the nurse in charge either co-operated or looked for another job.

Furthermore, my academic supervisor insisted that this was a unique opportunity to gather rich and meaningful data. It was not easy to work in this environment, especially when I found myself counselling and supporting the nurse-in-charge who was possibly forced into looking for a new career direction as a direct result of the project. Webb (1989) discusses how there is a need for emotional support for the action researcher in the form of a confidant and mentor. I believe this is because the researcher is expected to form close and special relationships with the participants in a collaborative inquiry and is under enormous pressure.

I would advocate the need for emotional support and reiterate that this does not have to be the research supervisor. The essential issue is that the emotional support for the researcher should be recognized as legitimate and consideration given to the availability of someone to fulfil

this role. The action researcher is also concerned with the difficulties in maintaining anonymity and confidentiality.

ETHICAL DILEMMAS ASSOCIATED WITH ANONYMITY AND CONFIDENTIALITY

Action research is often written as case studies and as such confidentiality and anonymity are potential problems to be explored with participants. In a collaborative enquiry the participants are supposed to *own* the findings which are constantly fed back to them by the researcher. In my study, participants had transcripts given to them after interview and were invited to change any aspect that they did not feel comfortable sharing with others. Other findings were discussed at weekly multi-disciplinary meetings where action was planned and reviewed. In situations where I felt the participants might be particularly vulnerable, I discussed sharing the chapters of the thesis as it was written, but possibly owing to the degree of trust established, or to complete lack of desire to have further contact with the study, this was not taken up by any of the participants.

However, whilst the researcher can assure participants that no one will be named in the thesis, the researcher cannot control what participants say to each other in the field and, as such, vulnerability of individuals may become an issue.

Anonymity and confidentiality are also compromised by the fact that the researcher can easily be associated with having worked on a particular ward during data collection and therefore many people within the organization reading the finished thesis are likely to be able to identify key players. This makes writing up of the research particularly difficult. As the nurse in charge said:

> It is like someone coming into your flat and rearranging the furniture it's like having to do your dirty washing in public.

Whilst it is possible to take some measures to limit the potential damage of this type of research, the real issue for me has been whether it is immoral to make participants vulnerable to the unknown in such a public manner and call it research! Action research has its own ethical issues but also some practical dilemmas of concern to the researcher.

In the last part of this paper, I would like to address two of these difficulties: firstly, the difficulty of changing practice with an ever-changing workforce and, secondly, the difficulty of combining action research with the academic pursuit of a higher degree.

Difficulties of changing practice with an ever-changing workforce

In collaborative research it is essential that participants volunteer for the proposed change and the researcher needs to constantly renegotiate his/her facilitating role. For me this was made harder by an ever-transient workforce. During the period of the study 85 new staff members arrived and 89 left, representing 174 disruptions to the ward over the period of a year! I question whether it is really possible to have true collaboration when working with a team of different people, who may wish to engage in the research at different levels thus affecting the possible outcome of the innovation for others. As one participant commented:

> It's talked about every week, it's such a shame it's not followed up. I don't really see anything being done. I've spoken to a few patients about it. I mean I feel ashamed, I would have liked to do more, I should have done more, I could have done more, you know with patients, I mean I've spoken to a few but I should have taken it a bit . . . again it's that thing, you're only here for 3 months you know and it would be nice if it was a continuing thing — something you could follow up yourself when you move on to the next job.

The practical issue for me was gaining collaboration from a number of people passing through the ward who were under an obligation to support the innovation because their immediate manager had agreed in principle to the project. What began as a 'bottom up approach' rapidly became 'top down' which was contrary to the ideals of action research. Finally, I would like to consider another possible dilemma for the collaborative researcher, namely the difficulty of combining action research with the academic pursuit of a higher degree.

Difficulty of combining action research with the academic pursuit of a higher degree

The first point I would wish to make here is that action research does not give you any easy ride and there may be quicker ways of gaining a PhD. Working for a higher degree is at times extremely isolating and one can be riddled with self-doubts. No research follows a straight path but most research can be planned in advance and the researcher has some sense of direction and purpose. With action research, the researcher can only plan the approach in advance and has to learn to develop methods and strategies in the field.

Energies are taken up not only with data collection but also with facilitating change. It is an exhausting process and, once started, because there is no natural end, can be difficult to withdraw from. Having spent 6 months gaining research access, and having worked on the ward every day for a year, it took a further 6 months before I felt able to relinquish contact. This was then only made possible because one of the participants had gained monies to

continue the evaluation and later gained a Department of Health PhD studentship to further the investigation into lay participation in care. One year seemed such a small amount of time in which to achieve any meaningful change and it seemed inappropriate to withdraw from the field until support was no longer needed.

Another demand on time and skill was made by the triangulation of data which included copious daily field notes, qualitative interview transcripts and various other more structured quantitative measures which required computerized statistical analysis. It is not uncommon for those engaged in collaborative research to use mixed methods, but the demands this places on the researcher should not be underestimated.

Another issue of combining action research with the academic pursuit of a higher degree is that there are not many academics who share the underlying philosophies and appreciate the value of collaborative research. This can make the writing-up phase difficult when trying to share a different type of knowledge through the constraints of a traditional academic thesis.

CONCLUSION

In this paper I have tried to focus on the emergence of action research as an example of collaborative research within the practice discipline of nursing. I have attempted to highlight the scientific merits of action research in producing a different type of knowledge more appropriate to a practice discipline.

At the same time, I have also wanted to share some of the practical issues and dilemmas of utilizing this approach in reality, in the hope that this honest portrayal will help others develop more appropriate methodologies to bring true collaboration to fruition.

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